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CHILDREN

AN INTERDISCIPLINARY JOURNAL FOR THE PROFESSIONS SERVING CHILDREN

november • december 1971

involving parents in a children's clinic
adolescent maternity services
intercountry adoptions
fighting sickle cell disease
teenagers discuss age restrictions

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Play is part of the therapy program for this young patient with sickle cell anemia, as he recovers from a painful crisis episode in Freedman's Hospital, Washington, D.C. The outlook for children like him brightened in 1971 as HEW undertook a nationwide $6 million attack on the fatal disease that affects 1 in every 500 black Americans. In this issue CHILDREN looks at recent advances in diagnosis of sickle cell disease (p. 222) and nursing care of affected children (p. 227).

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Involving Parents in a Children's Clinic

Eugene Langellotto

The activities of low-income parents of children and youth served by a comprehensive pediatric clinic in Baltimore, Md., illustrate how clients can be included in the structure of a health project when staff members listen to their ideas and encourage them to speak and act for themselves.

The project is officially called the Comprehensive Pediatric Care Center, but the families it serves usually refer to it as "the clinic" or "the Baltimore Street Clinic." It is located in a low-income area of East Baltimore that encompasses two large public housing developments. About 1,100 families with more than 3,200 children live in the area.

The pediatric clinic was established in 1965 through the coordinated efforts of the Baltimore City Health Department and the Greater Baltimore Medical Center, with Federal support through the program of comprehensive health care for children and youth. The building in which it is located also accommodates a variety of adult clinics and a day care center operated by the Baltimore City Department of Social Services. A shuttle bus plies between the building and an outlying hospital, which provides the project with backup diagnostic services and inpatient care.

The pediatric clinic employs a full-time interdisciplinary staff consisting of three pediatricians, one of whom serves as project director; three registered nurses and two nursing aides; three social service

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workers, one a professionally trained social worker with a master's degree, one an agency-trained social work assistant with a bachelor's degree, and one a high school graduate from the community who has been trained as a community health aide; a dental assistant; and five clerical workers. Three dentists who specialize in serving children are employed part-time. Part-time consultants include a psychiatrist, a psychologist, a nutritionist, and a hearing and speech specialist.

Early in the clinic's operations those of us who comprise this health team realized that to provide adequate health service we needed to learn more about how our patients live. While most professional workers subscribe to the theory that you cannot treat a patient in a vacuum, experience has shown that in a large medical institution a vacuum is often created by the health professionals themselves, who often work with far too little understanding of patients' needs and circumstances—because of the staff workload, the location of the clinic, which is often far from the patients' home neighborhoods, and other reasons. The doctor or appointment clerk, for example, may be unaware that a patient's reluctance to make or keep an appointment is due to lack of money for transportation to the clinic, the fear that a long waiting period there will mean losing a day's pay, or just because a child or his parent has no coat or shoes to wear during the trip to the clinic. Fear of the hospital or the doctor can also be an impediment to service.

Our pediatric clinic overcomes some of the disadvantages of large hospital complexes: it is small—and therefore less frightening—and it is located within walking distance for most of the patients. Nevertheless, from the first we found some of the same deterrents to service that a large medical facility experiences.

Broken appointments

In the early days more than 50 percent of the appointments we gave were not kept and few patients responded to reappointments. The social service staff members were determined to find out why. We began to learn more about the families by visiting those in which a member had missed a clinic appointment.

Our approach was to let the children's parents know about our concern for them and to encourage them to talk about what was important to them.

For example, we usually introduced ourselves in somewhat the following way: "Mrs. Black, I came to visit you today because I wondered why you missed your child's appointment last week. I thought maybe you had some trouble—would you like to tell me about it?"

Most of the parents answered willingly. Some said that they had been unable to keep their appointments because they had no one to care for their preschool children or that the appointments were set at times when they had difficulty in getting away from home or work; others said they had been given different appointment times for each of their children, thus requiring them to make repeated visits to the clinic. Some mothers complained of long waiting periods before seeing the doctor, while others said their second appointment had been with a different doctor than the first. One woman said, "Mister, them doctors just experiment on us poor people."

The clinic's response

Getting our patients to know us was a first step in gaining their confidence. As we met the families in the neighborhood, we found that most were unaware of the health resources available to them. We also learned that their image of illness was usually one of total incapacitation. Only when one of the parents could no longer fulfill his or her daily obligations and responsibilities was he or she regarded as "sick."

For example, a worker visiting a 45-year-old mother of four children noticed that the mother walked with an obvious limp. When asked about it, the mother replied, "Honey, this old hip has been bad for years, but I feel pretty good except on rainy days."

We discovered that most families knew little about the causes, treatment, and course of various diseases. They consulted the local druggist for advice about their ailments, or relied on their collections of patent medicines for cures.

Neither the parents nor the children had previously received regular dental treatment or preventive dental care. Because they visited the dentist only when in pain, most of the adults and older children had had several teeth extracted.

Thus, we found that the families generally put a very low value on health care. With meager incomes, their first aspirations were centered on finding better living quarters and securing much needed clothing and household articles.

We also found that most of the families had cut themselves off from the community. Distrustful and suspicious of other people, they were listless and and seemed to have lost the power to take initiative. Unorganized among themselves, these parents did not

interact with others in their family units either.

With a new understanding of our patients' families, we were ready to design a better plan for meeting their health needs.

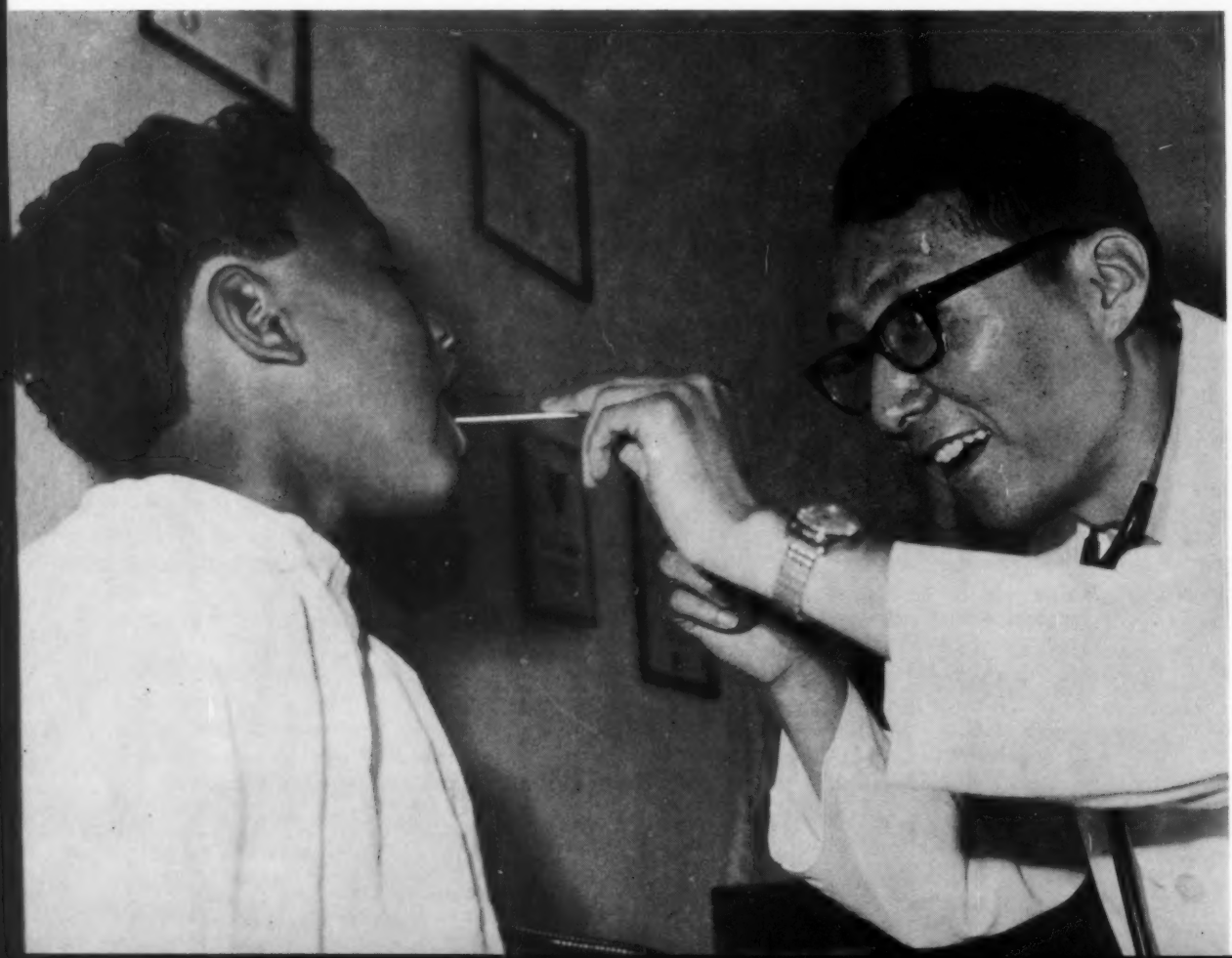
First, we dealt with the problem of broken appointments by employing a neighborhood resident who had been trained as a community health aide. Her duties include visiting the families for the following purposes:

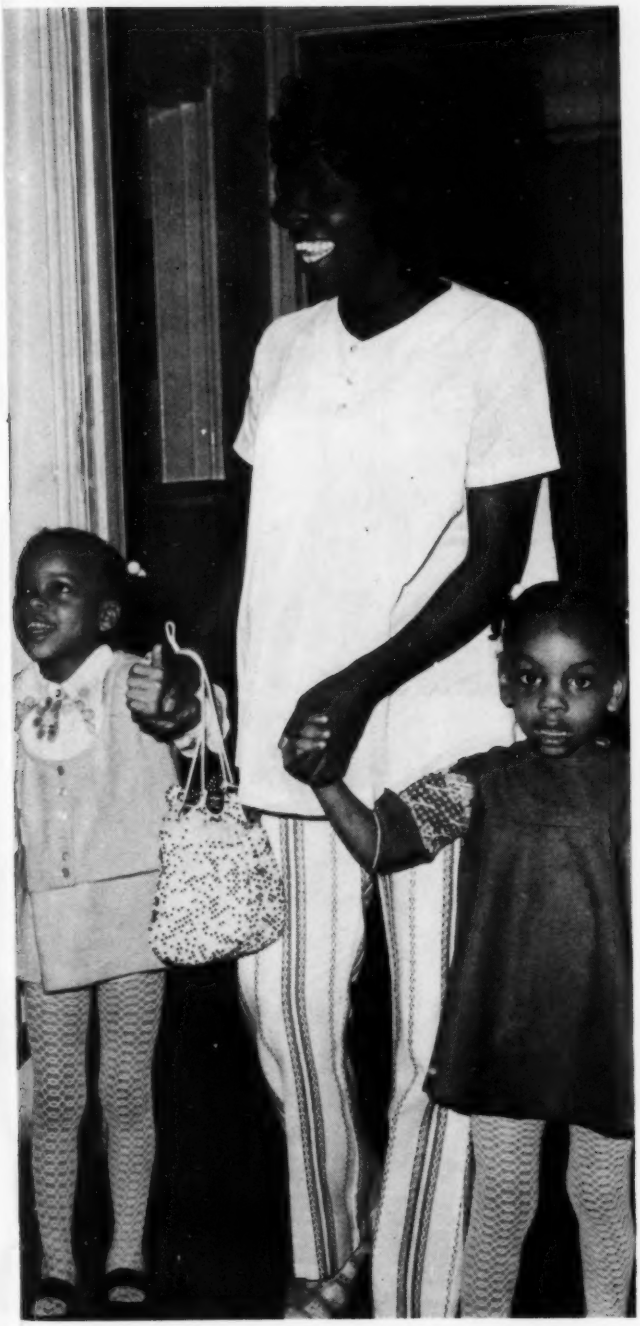
- ☐ To deliver information about their first appointment and at the same time to describe the clinic's program.
- ☐ To look for obstacles that might prevent the family from clinic attendance and, when possible, find ways to overcome them.
- ☐ To help the family keep its clinic appointments. This often means changing the time and date of the appointment on the spot, and in some instances, helping the mother take the children to the clinic.
- ☐ To seek out families known to have a sick child and encourage them to bring him to the clinic.
- ☐ To tell the social worker about family problems with which she was not able to deal.

As a result of the community health aide's efforts, the clinic registered a significant reduction in broken appointments. The staff began consulting the parents about convenient times before appointments were made, and members of a family were given consecutive appointments on the same day whenever possible. Parents now keep 61 percent of their children's scheduled appointments, compared with 50 percent before the health aide began work.

Second, we took steps to acquaint the people in the community with the resources available at the pediatric clinic. Members of the clinic team spoke at community group meetings, extended invitations to parents in the area to visit our clinic, and distributed a descriptive pamphlet to every tenant in the housing developments.

Many parents complained that no day care facilities were available for their preschool children. Since the day care center in our building was unable to accommodate any more children, we asked the Department of Recreation to operate a day-recreation program for preschoolers in our clinic two mornings each week. Our request was granted. The program





Staff members of the Comprehensive Pediatric Care Center, located in a low-income area that includes two large public housing developments, were concerned about the number of patients who did not keep their appointments or return for second ones. They decided to find out why—and to learn more about their patients' needs and circumstances. The rapport established can be observed as two young patients enter the clinic (above) and another is examined (left).

has given more children an opportunity to participate in supervised group activities and has given their parents some free time.

From 8 to 24 preschool children attend each session of the day-recreation program. In addition to participating in arts, crafts, and games, they visit various interesting sites in Baltimore. A trip to the zoo provided most of these children with their first glimpse of many live animals.

The Department of Recreation staff was so pleased by the success of this day-recreation program that it has expanded its regular summer camp program to include preschool children.

In May 1968, the medical director offered the parents a meeting place in the clinic where they could come evenings to discuss their mutual concerns. Leadership was provided by clinic team members and the parents were informed of the meetings through posters and personal letters of invitation.

From 18 to 31 parents met monthly with the clinic director during the first series of meetings. Parents were encouraged to state their complaints and to comment on how the clinic's services could be improved. They also heard guest speakers discuss topics of special interest.

In subsequent meetings several parents within the group began to take the initiative in doing something about their common problems. Being together and knowing that others were interested in them seemed to help these parents take action on their own.

For example, a group of mothers who participated in the meetings banded together to demand better equipment for the laundry rooms of the housing developments in which they lived. Eventually they succeeded in obtaining the improvements they wanted.

When one mother learned of the tenants' attempt to replace obsolete refrigerators in a neighboring housing development, she worked with the chairman of that group and was able to get a commitment from the city commissioner of housing to furnish new refrigerators in both areas. This success was exciting for parents who had complained that their own tenant council had "never done anything for us."

As the parents became more involved in common pursuits, several of them expressed their concern about an unprotected gas pipe that passed over a stagnant, 50-foot-wide waterway near their homes. Many children crawled upon the pipe, and one child had recently fallen from the pipe into the mud below. The parents wanted to know how to correct the situation.

With the help of the social worker, they made inquiries of the city and the gas company, but no one

would admit ownership of the pipe. After many letters and phone calls, gas company officials acknowledged responsibility for the pipe and offered to meet with the parents to discuss the situation. At the meeting the representatives of the gas company offered a choice of remedies. The parents decided that the pipe should be fenced in to stop children from crawling or playing on it, and this was done.

Parents' Club

As the parents continued to meet with the medical director and social worker, they decided to name their group the Parents' Club of the Baltimore Street Clinic, and to take steps to attract other parents to the pediatric clinic.

When summer arrived, attendance at the parents' evening meetings dropped. The parents who continued to come to the center decided to meet during the day. Since the parents had voted to change the time, the medical director agreed—not recognizing that the new hour would further restrict attendance of the fathers and mothers who worked. The day meetings generally drew about 10 mothers, most of whom received public assistance.

The group then offered to prepare a publication that would help make the community aware of the clinic's services. The *Clinic and Community Caller*, an 8-page newsletter that also contains many photographs of neighborhood activities, became a reality in June 1969. Six parents worked with the clinic's social work staff to get the factual information and photographs and write the articles for the newsletter. A father contributed illustrations. *The Caller* appeared regularly each month for almost a year.

Then the parents were informed that the newsletter would be discontinued because the clinic budget had been cut. The parents, who had developed a sense of pride and achievement in their publication, faced

Parent volunteers supervise young children in the waiting room of Baltimore's pediatric clinic, which is supplied with toys and a television set purchased with money raised at a concert held by the Parents' Club.

this crisis by deciding to raise the money themselves. They held a fund-raising concert in the community that brought in $1,236. Impressed by the parents' priorities, the clinic administrators readjusted their budget to include money for the newsletter for the fiscal year beginning July 1970; therefore, the special funds were not needed.

It soon developed that a monthly newsletter was too much work and the parents decided to issue *The Caller* bimonthly. Since July 1970, the publication has appeared every other month. A mother serves as the editor with almost no help from the social work staff. Two parents and two children do the art work for each issue. Other parents furnish material about community activities and the clinic supplies information on health education and clinical services.

The newsletter has been a motivating force in helping the parents' group grow and in establishing the clinic more securely in the community.

One outgrowth of *The Caller* has been a series of art exhibitions of works of parents and children. The first show was held in the clinic on a Sunday. It included, in addition to oils and watercolors, items the exhibitors had created from waste materials—for example, animal figures made from egg cartons and jewelry from chicken vertebrae. Seven parents and 12 children contributed exhibits.

The experience of finding that others were interested in their creations prompted the parents to make their own arrangements for a second exhibit, which was held in a housing project. It was so successful that it promises to become an annual event.

The success of the fund-raising concert helped the members of the Parents' Club gain a great deal of recognition in their neighborhood and nearby areas. Soon parents were being asked how the money would be used. They decided to supply the pediatric waiting room in the clinic with a television set and toys, so that the children waiting to be examined could be entertained or occupied. The costs of installation and an antenna were paid for by the clinic.

It was not very long, however, before the toys were broken and had to be replaced. The parents realized they did not have enough money to continue to supply the waiting room with replacements for broken toys. Therefore, in the spring of 1971 two mothers volunteered to supervise the children's play activity in the waiting room, a duty they have continued to perform.

Recognizing their ability, a social worker arranged for the volunteer mothers to attend a Children's Television Workshop seminar where they could increase their knowledge and skill in working with young children. This resulted in the pediatric waiting room being selected as a "Sesame Street" viewing station. Equipment used in the "Sesame Street" programs is now given to the pediatric center, thus eliminating the need to spend more money on toys.

Although the two mothers started as volunteers, the professional staff felt that they should not continue to work without pay. Therefore, the center applied for Work Incentive Program traineeships. Since August 1971 the two mothers have received a small wage from the State.

Other activities

The Parents' Club is now formally organized with elected officers. Meetings have been shifted back to evening at the request of parents and regular attendance has grown to 24.

Other activities and services have resulted from the formation of the Parents' Club. When members of the club compared the services of the pediatric clinic, which is operated for their children every weekday, with the services of the medical clinic for adults, which was then operated 1 day a week, they began to prod the adult clinic's staff to expand services. From these suggestions, a prepaid medical assistance Family Care Program was developed. Parents' Club officers appointed two members of the temporary advisory council; later the council will be elected by the people enrolled.

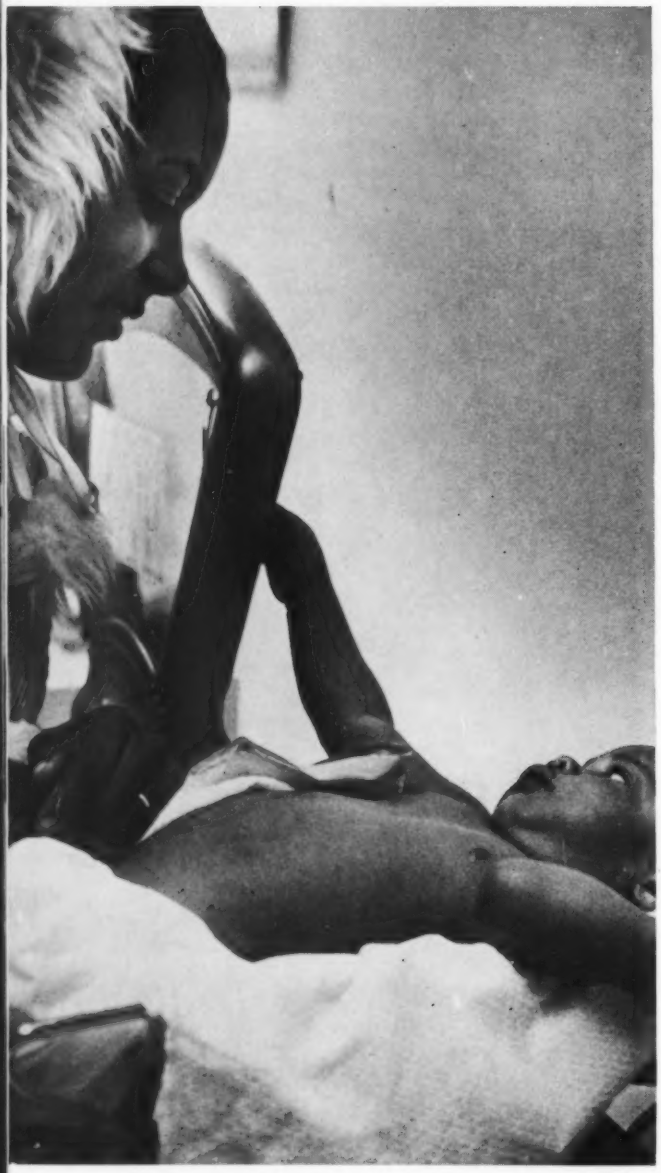
More than 500 people have signed up for the Family Care Program since it was launched in April 1971. This has enabled the center to increase its services to the community by hiring a full-time staff for the medical clinic, with an internist on duty 5 days a week.

The parents are also responsible for the employment of neighborhood youngsters in the pediatric clinic. In the spring of 1971, parents suggested that two students from each of the two housing projects be employed in the clinic for the summer. Along with the request came the suggestion that the Neighborhood Youth Corps pay the salaries of the students—an idea the clinic staff found most attractive. The administrators not only accepted the suggestion, but also found jobs for six students instead of four.

Now the Parents' Club has begun to operate independently, drawing on the experience its members have gained in making their own decisions. The club has also demonstrated to other parents that administrators of the pediatric center are willing to listen to the people they serve and to act on what they hear.

ADOLESCENT MATERNITY SERVICES:

Eleanor W. Smith Anne Duncan Judith Weatherford Shouse Richard C. Brown



A new mother brings her infant to the well baby clinic at Children's Hospital for a monthly followup visit, one of the many services provided by the Adolescent Maternity Center.

Pregnant students—married and unmarried—have been a great concern of professional health workers for some time. Not only are there greater numbers of adolescent mothers, but they are becoming more visible in all socioeconomic and racial groups. Most unmarried girls no longer conceal their pregnancies by leaving their communities, and more girls are keeping their children, regardless of marital status.

Thus, the immediate needs of the pregnant girl have ceased to be our sole concern. We are now concerned also with her future ability to mother, her maturation into womanhood, and her new function in family, community, and society. We have searched for the best ways to allow her to explore these changes in her roles for herself. Based on our experience, an interdisciplinary team approach appears to be an appropriate method of helping the young mother deal with the multiple tasks she faces.

The center setting

The Children's Hospital Adolescent Maternity Center opened in San Francisco in September 1967. It is supported by the San Francisco Unified School District, Children's Hospital of San Francisco, and occasional voluntary contributions. As an academic, medical, and social service program, it has now served about 400 pregnant young girls and their families.

The girls come from all income levels and racial and ethnic groups, and from all geographic areas of San Francisco. They come to us on referral of their doctors, their schools, and other agencies. As our Center has become better known, more girls are also referring themselves, often as soon as their pregnancy is confirmed.

About half of the girls are married when they enter our program. Nearly all keep their babies now, in contrast to the 10 out of 100 girls who placed their infants for adoption during the first year of the Center's operation.

The Center program includes a school for the girls, with junior and senior high school classes held in a building on the hospital grounds from 8:30 a.m. to

A TEAM APPROACH

1 p.m. weekdays; a maternity clinic for prenatal care and post-partum followup; and a well baby clinic designed to follow mother and child for the first 2 years. In addition, the students meet with nurses, social workers, occupational therapists, dietitians and academic and vocational counselors for group discussion and individual guidance sessions.

New fathers are invited to join some of the Center talk sessions and meetings are also held for the mothers of students so they too can discuss shared feelings and problems.

Most students continue to attend the Center school for a short period after their babies are born. While they attend classes, their infants may be cared for in a nursery that is part of the Center program.

The Center is a community where adolescent struggles with personal identity and relationships with others can be worked out with girls in their own age group and situation, where adults listen, attempt to understand what young people are saying, and support the problem-solving processes. It is a place where a young woman finds herself first observing and then involving herself with both other students and adults in the program.

Members of the Center team encourage this involvement. They allow themselves to be observed at work, to be questioned, to be challenged, to be responsive in the whole interaction between themselves and the young people. This sense of community is of vital importance in supporting the young person's development and social maturation.

Such specialized, comprehensive service is needed because the young women in our program are still in the active process of maturing on multiple levels. The tasks and responsibilities they face are great. Our program aims to help them and their families deal with the many pressures of their new—and in many instances, premature—roles as wives and mothers. We feel that this kind of help is the right of all school-age parents and their children.

The goals of our program are threefold:

☐ To offer a pregnant young woman opportunity and encouragement to develop her inner strengths, examine her alternatives and make the best choices to meet her needs and those of her family; to help her mature; and to foster her feelings of hope for the future.

☐ To assure mother and child the best obstetrical care and knowledge obtainable during pregnancy and to motivate young families to continue to pursue medical care.

☐ To offer a young mother opportunity to continue her public school education; to encourage her to approach education as a means of self-realization; and to aid her and her family in developing future educational or vocational plans.

The interdisciplinary team

We feel that close interaction among disciplines best serves the broad needs of our young people. Our team consists of a basic core of individual professional members who are directly responsible for the educational, social, and health needs of the young families with whom they work. These three—teacher, social worker, and nurse—are responsible to the individual girls and, in turn, to a group of hospital and school district administrators who determine Adolescent Maternity Center policy.

The hospital pediatrician, obstetrician, and other staff members, of course, are also involved in the interdisciplinary team. Dr. Gilbert A. Webb, Chairman of the Department of Obstetrics and Gynecology of Children's Hospital, who was responsible for initiating the Center program at the hospital, and Mrs. Elaine Wolfe Grady, Director of Special Service Centers, San Francisco Unified School District, who originated the idea of the Center, play strong supporting rules.

Eleanor W. Smith is coordinator of the Adolescent Maternity Clinic on the staff of Children's Hospital of San Francisco and clinical instructor in nursing at the University of California, San Francisco. **Anne Duncan** has been the head teacher at the Center school since its inception in 1967. **Judith Weatherford Shouse,** a clinical social worker, also began with the Center team in 1967. **Richard C. Brown, M.D.,** is a Youth Service pediatrician at Children's Hospital.

The core staff meets at least twice weekly, maintains daily communication with each other, and continuously consults with other members of the staff. In addition, others who work in the Center, either as professionals or volunteers, also attend a weekly staff meeting. Conferences are held following student visits to the Young Families Well Baby Clinic and the Adolescent Maternity Clinic. These involve the pediatrics and obstetrics consultants and residents, as well as nurses, social workers, dietitians, and volunteers.

To further develop a feeling of community, a weekly meeting of the student body is held. The meetings, which are also attended by core staff members, serve as a forum for sharing information and developing problem-solving and leadership qualities. Every effort is made to keep communication free and open among staff, students, and administration.

The handling of a sudden complication or tragedy affecting one of the girls in our program illustrates the team's use of open communication. Pregnant girls in our Center grow very close to each other because of their shared experiences and concerns. News spreads rapidly throughout the Center community, and rumors become distorted as they disseminate. We have found that the best way to relieve such a situation is by offering accurate information and then encouraging discussion of the facts. The team nurse is responsible for gathering all the medical facts about a situation, communicating them to members of the staff, and then to all the young people. All of the staff encourage discussion of the information and, most important, exploration of feelings.

For example, 16-year-old Jane's baby was born with twisted and deformed feet and legs. The infant was to have casts put on her legs on the second day of life. If the casts did not correct the deformity, the baby might later need surgery. The prognosis was good, but it was thought that months or even years might pass before the final correction would be completed.

The nurse talked with the obstetrician, pediatrician, and orthopedic surgeon and discussed with Jane her understanding of what she had been told and helped her to express her anxieties and fears. She then informed all members of the staff and the young women in the program. Through open discussion in groups and individually with each other, the girls became able to express their own feelings and also to understand Jane's feelings. Instead of avoiding Jane, her closest friends initiated communication with her by visits and telephone calls. When Jane returned to school she was able to discuss her experiences and her feelings with the whole community.

We were able to share her pain and eventually her joy when, in only a few weeks, the casts successfully corrected the baby's deformity.

Pregnancy during adolescence

When pregnancy occurs, the adolescent's normal striving toward independence is distorted and disrupted. She has been struggling with her need to become an independent person, to break away from her family, while still needing its support in many ways. Because all the material and emotional needs that normally evolve during pregnancy are accompanied by a concomitant desire for independence, the young woman often suffers great anxiety and conflict.

A young girl also responds intensely to the normal physical changes which occur during her adolescent years. When pregnancy is superimposed on this already stressful phase of development, she becomes acutely sensitive to the greater alterations and distortions of her body. These uncontrollable changes of adolescence and pregnancy produce feelings of anxiety about herself as an emerging woman and mother.

While one young pregnant girl will wear a tightly buttoned coat throughout the day, regardless of activity or weather, another may appear unaware of her changing figure and continue to wear clothing which no longer fits. Many pregnant adolescents do not wear maternity clothes because they "look like they are for old women" or, as one girl explained, "Those clothes just hang on you like sacks".

Mastery and control over her emotions as well as her body is another concern of the adolescent. This, too, is intensified during pregnancy. A young girl feels helpless about what is happening to her and anxious about what will be done to her. Through anticipatory guidance she may be helped to attain a sense of control over or mastery of the tasks which confront her. The processes of labor and delivery can be made comprehensible and less frightening, so that she will be able to utilize the helpful information made available to her.

When the young mother successfully meets the challenge of giving birth, when she feels that she has accomplished this adult task with dignity and self-control, she is better able to move on toward motherhood. If her own needs are met, she is usually able to become a giving mother and to achieve a relationship with her child that will be a foundation for continued healthy development.

Hopes and fears regarding parenthood are aired by young mothers and fathers as they meet with members of the hospital staff and the Adolescent Maternity Center team at Children's Hospital of San Francisco.

An adolescent girl who has rarely experienced physical pain and hospitalization may be very fearful of hospitals and health workers. Or she may have had an experience which she recalls as frightening and is now suspicious.

The only experience Gladys, now 15, had had with a hospital, for example, occurred when she was 8 years old and had broken her arm. Gladys remembers what seems to her to be long hours of waiting in an emergency room in great pain, with no one interested in helping her. Once pregnant, Gladys was so fearful of doctors and hospitals that she did not go to the clinic for her prenatal visits until her classmates convinced her that she must. The first time she visited the clinic, she could not tolerate the waiting for care and left before being seen. The social worker discussed her difficulties with her and, through role playing, helped her to formulate the questions she wanted to ask the doctor. When Gladys reached the clinic a second time her anxiety returned and she sought out the nurse, demanding that the nurse ask these questions for her. The nurse assured her that she would be present in the clinic and ready to help her, but that she was certain Gladys could ask these questions herself. Gladys again reviewed her questions and then was seen by the doctor. Thus, through the support of her peers, the social worker and the nurse, she took the final step toward feelings of trust and confidence in health services personnel, a step which will be of lifetime value to her and her family.

Another important aspect of adolescence is that of achieving success in work and learning. Here the teacher on the core team plays a major role. Many students in the Center come to us handicapped by their lack of verbal skills. Often their previous attempts to learn or to adjust in the usual classroom setting have resulted in failure because of their feelings of inadequacy or inferiority. Pregnancy and its accompanying fears and anxieties are an additional complication. Until the anxiety is reduced, nothing meaningful can happen in the classroom. The warm acceptance of the teacher is not enough. Neither are the school's very small teacher-pupil ratios or the courses and texts that are tailored to individual students' levels of comprehension. It is the total climate, generated by all the disciplines working together and the support of her peers, that helps the individual girl to be willing to face the educational task.

In our program as much responsibility for learning as possible is given to the student herself. Within the firm ground rules and basic expectations of the teacher, the student may set her goals and thereby assume greater responsibility for her own learning, and for her success. Learning occurs more readily when the student finds personal gratification in her work, gratification derived from the attention, help, and honest praise given by the teacher and from her own mastery of meaningful work.

Another task during a girl's adolescence is the establishment of sexual identity as a woman and, in our Center, as a mother. The team facilitates this growth process from girlhood to motherhood, and appeals to the part of the developing adolescent which is striving toward maturity and adult responsibility.

A personal moral value system normally evolves during adolescence. Members of the staff are aware of this process and of their roles as models representing various value systems. For many young peo-

ple, acquaintance with staff members offers a unique opportunity to examine closely the values of adults other than their family members.

Developing a sense of the future is another feature of adolescent growth which assumes special importance at our Center. When a young woman enters our program, it is often with a deep sense of shame, guilt, failure and a pervasive feeling of helplessness and hopelessness. Her mother usually shares and confirms these feelings. Their sense of the future is in abeyance; the present defeats them both. A specific goal of the program is to help a young woman look toward the future, to develop her inner resources, and begin to feel a sense of mastery over her life. In her first interviews with the staff she is asked about her ambitions and goals. Often the reply is a helpless shrug, and, "Well, I always wanted to be a teacher, but now. . ."

As time passes, the young woman is frequently and positively confronted with a need for future planning. Choices of academic or vocational pursuits are presented by skilled counselors who suggest achievable goals and realistic plans for accomplishing them. The student aspires to and reaches academic goals, perhaps for the first time in her life. The adult achievement of bearing her child results in a sense of pride which often increases her good feelings about herself and may expand her ability to cope with future life tasks. Such achievement, reinforced by all disciplines, affirms her hopes for the future.

When Arlene, a 14-year-old girl attending the Center, described the lives of her two unwed sisters—21 and 24 years old, one with five children and one with eight, and both seemingly helpless to change their lives—she said, "It's not going to be that way for me." This was the beginning of her understanding that she had the responsibility and, more important, the ability to control her future and to direct the course of her life.

The girls view the team

The interdisciplinary team presents a choice of adults to whom the young pregnant woman can relate at various times and in various ways. When a team has demonstrated care and concern for her, she may be able to trust one or all members, or she may want to transfer her trust from one team member to another as her needs change. For example, a girl may have established a trusting relationship with her social worker, who has helped her to deal with her problems realistically. Then, as her delivery approaches, she is overwhelmed with fears and anxieties about what this experience will entail, and by feelings that she has been unable to deal with earlier because of her many other pressing problems. At this time she may turn to the nurse for information, help and support. Later, as the young mother prepares to return to regular school and becomes most concerned with her future academic career, she may seek the help of the teacher, who is the individual most able to provide what she now needs.

Sometimes a young woman finds only one adult to whom she can relate in a trusting way. When she chooses to use the team in this manner, by relating to one individual only, the other team members can often help through communication and consultation, and by provision of surrogate care and support when the trusted individual is unavailable.

The trusted team member must exchange information with other team members so she can gain a wider perspective on the total care of the young woman. An even more difficult responsibility is to use her relationship with the student in a positive way.

Acting in the capacity of the good parent, she makes every effort to give the young mother the support and security that she so desperately needs. Simultaneously, her goal must be to increase the young woman's feelings of personal worth and self-confidence, so that she may move on to trust others. In this way the student is prepared to eventually separate from the trusted person and the sheltered community of the Center. Such a core task is reminiscent of Helene Deutsch's statement that the tragedy of motherhood is that the mother must begin to separate from her child even at the moment of its birth.[1] The professional worker, just as the good mother, provides support but prepares for separation by fostering trust in others and by promoting growth and maturity.

By allowing the young woman herself to choose the way in which she will use the team, we give her real alternatives and freedom to find what is most acceptable to her to meet her own needs. At the same time that she is experiencing this independence and ability to make choices, she is supported by the knowledge that there is a team that knows her, cares about her, and upon whom she can depend.

Most important, though, for the adolescent mother is the fact that the interdisciplinary team provides an approach to the care of the whole person. A combined concern for her physical, emotional, social, educational, and occupational needs can only be provided by a group of professionals whose varied ex-

pertise is directed toward an understanding in depth of the many aspects of her needs and who can promote care for the whole spectrum of needs with sensitivity and skill.

Members view the team

When, for example, a staff conference was held to discuss similar problems of three young students in the classroom, staff members were hoping to identify the difficulties and discover interventions that could be used to resolve them. All three girls had attended school for only a few weeks and were seemingly unable to relate to the other girls and staff. Their attendance was poor and they were not participating in group work. However, a pooling of observations and information among staff members disclosed that the three young women presented differences rather than similiarities—in their present family problems, in their past experiences, and in the stages of their pregnancies and the physical and emotional changes related to these stages. Such differences in the stresses that these young women were experiencing suggested very different interventions in the care of each. Without the interdisciplinary team conference and the opportunity to share information and expertise, the school's teachers would have continued to struggle with behavior which really was not related to academic stresses but to physical and emotional problems.

The interdisciplinary team approach thus affords many advantages for the pregnant young woman. Her involvement with staff and peers supports her during this stressful time in her life.

However, the time comes when she must leave the Adolescent Maternity Center, must leave the shelter of a special program, and must deal with the problems of this separation. Her process of termination is like that of any person experiencing a loss of someone or something that has been very meaningful to her. Every girl goes through the mourning process in varying degrees, reacting with anger, denial, and sorrow before reaching a resolution. Similarly, staff members react to the loss of young people with whom they have developed very close relationships. They continue to see many girls informally when they visit the school or bring their babies in for care. Even though the young mother moves on into new experiences, she often needs to return in some way to what she has left behind, to reflect on her experience and to further integrate it into her maturing self. Thus she achieves a renewal of hope and confidence for her own and her family's future.

While the interdisciplinary team approach seems to provide many advantages for the pregnant adolescent, it makes certain unusual demands on team members. Each staff person must be willing to be used by patients in ways that may differ considerably from the expectations gained from his own professional education. Although many professions give lip service to the team concept, few actually understand the changes which it produces in professional functioning and in patient-professional relationships. As Dr. Jessie Bierman wrote,

"There is much talk and some practice of what is called the multidisciplinary approach to problems these days. But just because members of several disciplines are brought together does not necessarily mean very much. They sometimes remind me of two-year-olds playing together. It is really parallel play rather than any real communication or learning from one another. Our professional schools should be teaching us to play together at least on the three and a half-year level!" [2]

In addition to becoming more flexible in his relationship to the patient, the member of an interdisciplinary team must understand the work of other team members and strive to reduce the stereotypes he holds of professional colleagues. Trust and confidence in each other must also exist among the team members, who should accept each other as individuals who bring differing interests, abilities and life experiences to bear on the total care of the young family.

Summary

In a rapidly changing society the health professions must find new and appropriate ways to guide those who seek help in coping with their present concerns and needs, as well as ways to prepare them for their future life tasks. In no group is this more apparent or more important than with school-age families. No single discipline can deal comprehensively with the broad spectrum of needs of the young mother and her child. Our experience with an interdisciplinary approach has convinced us of its value both to young families and to the professionals who are involved in their care.

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[1] Deutsch, Helene: Psychology of women, a psychoanalytic interpretation. "Motherhood." Grune & Stratton, New York, N.Y. 1945.
[2] Bierman, Jessie M.: Some things learned. *American Journal of Public Health*. June 1969.

(A bibliography is available from Eleanor W. Smith, Children's Hospital of San Francisco, 3700 California Street, San Francisco, Calif. 94119.)

A Fresh Look at Intercountry Adoptions

John E. Adams
Hyung Bok Kim

Intercountry adoptions stimulate both enthusiastic support and vehement opposition. The proponents say the primary reason for such adoptions is direct humanitarian service to needy children and to prospective parents. The opponents argue that no child should be transplanted from his own culture, nationality, and race and asked to bear the burdens of possible rejection and loss of identity.

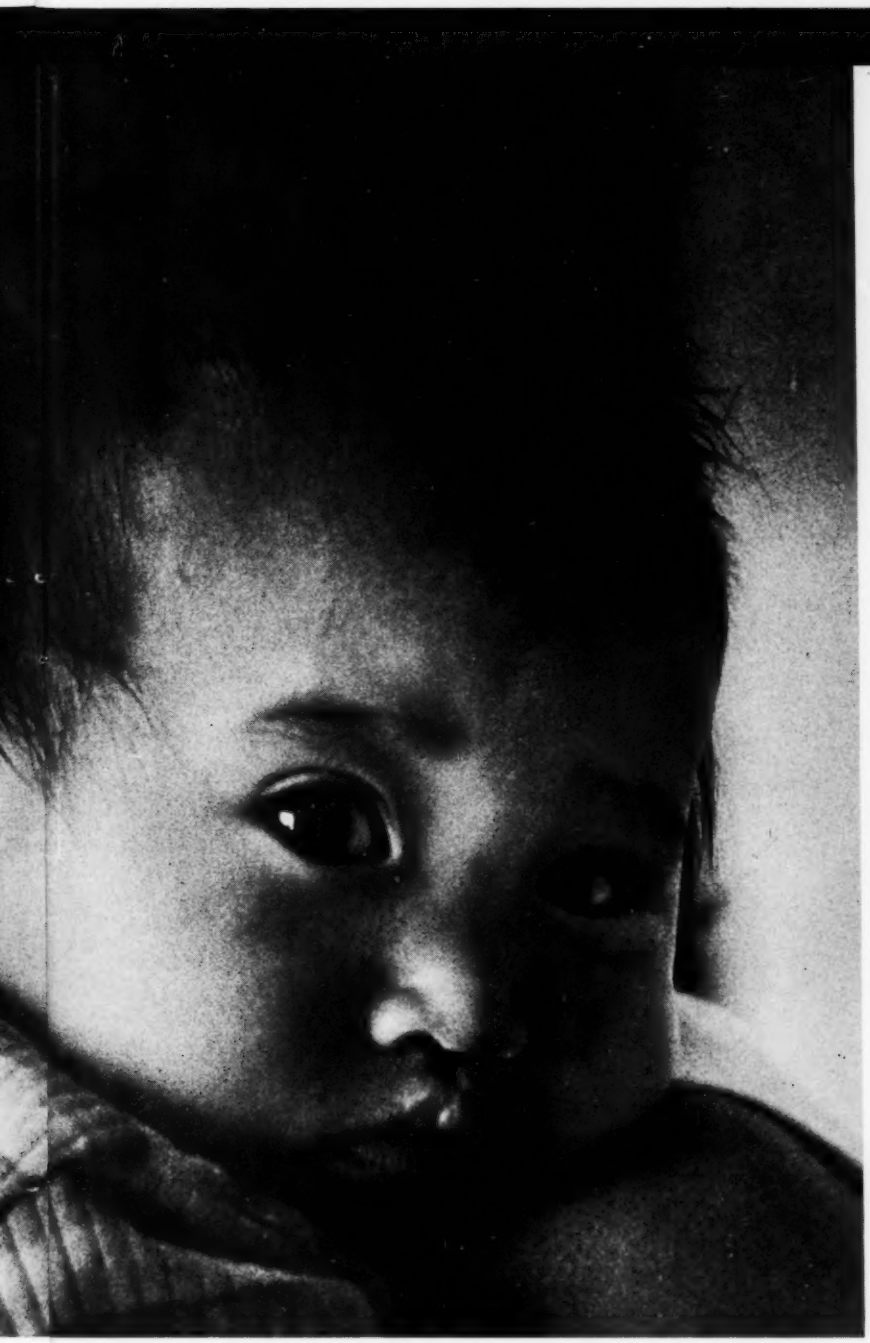
Even as the dispute rages, statistics show that intercountry adoption is now a well-established practice, although it had its beginning as an organized social service activity only within the past 25 years.

During this period better communication and extensive international travel have led to increased awareness of the needs of children in other countries. As a result, new attitudes of responsibility toward and acceptance of these children have developed. This new social awareness, together with the dramatic increase in intercountry adoptions in the past 3 years, suggests that the interest in such adoptions will continue to grow.

It seems to be a good time, therefore, to put the practice of intercountry adoptions into perspective.

First, such adoptions are becoming a significant part of the American child welfare scene. A comparison of the current level of intercountry adoptions by citizens of the United States—2,080 in 1969—with the current level of domestic adoptions—171,000 in 1969—shows that better than 1 adoption out of every 100 now involves a child from another country. Furthermore, the proportion of such adoptions is growing.

Second, American parents are not alone in the practice. Since



Europe's economic recovery following World War II, European parents have been adopting children from countries other than their own—first from Europe, then from Syria, India, South Vietnam, the Philippines, Korea, and most recently from South America. Our agency—the Holt Adoption Program, Inc.—alone placed more than 400 children from Korea in European countries during the 1970 calendar year. While no figures are available for the total number of intercountry adoptions in Europe in 1970, we think a reasonable estimate would be more than 1,000.

We use the term "orphan" as the U.S. Immigration and Naturalization Services does—in a legal, not literal, sense. The current law contains the following definition: ". . . an alien child (1) who is an orphan because of the death or disappearance of both parents, or because of abandonment or desertion by, or separation or loss from, both parents, or who has only one parent due to the death or disappearance of, abandonment, or desertion by, or separation or loss from the other parent and the remaining parents is incapable of providing care for such orphan, and has in writing irrevocably released him for emigration and adoption." [1]

If a child comes into the United States for adoption, the American citizens who are petitioning as adoptive parents must comply with all preadoptive requirements of the State of the child's proposed residence. If the adoption is to be completed abroad, both American parents must meet the child personally before or during the adoptive proceedings.

In either case, the Immigration and Naturalization Service requires the adoptive parents to obtain a visa for the child to be admitted to the United States. Before the visa is issued, a U.S. immigration officer makes an investigation of the child in his own country and, if the child is to be adopted in the United States, a licensed adoption agency in the United States makes an evaluation of the adoptive family.

U.S. immigration laws now permit adoption of orphan children up to and including age 13. A family may obtain up to two visas; exceptions are made when this restriction would mean separation of siblings, however.

Agencies involved in inter-

country adoptions usually place children without *known* parents. It is reasonable to assume, however, that many of the abandoned children do have living parents. Naturally, before adoption is considered, a responsible agency in the child's native country tries to follow up all leads to the identity of the parents and make sure the child is legally free for adoption.

The trends

Table 1 (this page) shows the broad trends in numbers and regions of origin of children from other countries adopted by parents in the United States since 1948.

During the 1948–1957 period, American adoption of immigrant orphans was primarily in response to an awareness of the inability of a devasted Europe to provide for its own children. Almost all children admitted to the United States for adoption between 1948 and 1953 came from Europe, more than half of them from two countries—Germany and Greece. Significant numbers of children also came from Italy and Austria. Beginning in 1953, a considerable number of Asian children began to be admitted to the United States—particularly from Japan and Korea.

We believe that although many countries were unable to care adequately for their children during this period, participation in intercountry adoptions was determined by two factors: (1) the presence in these countries of U.S. soldiers and other citizens who were aware of and concerned about the plight of homeless children; and (2) the foreign government's ability to regulate adoptions and its willingness to permit such adoptions.

It was the Refugee Relief Act of 1953 that originally permitted American families to obtain a visa for a child adopted by proxy under the laws of another country. Passage of this law signaled a new interest in U.S. adoptions of Asian children; at the same time adoption of children from Europe continued.

From a practical standpoint, proxy adoptions were the instrument by which thousands of children successfully found their way to homes of their own in the United States. The person most involved in this chapter of U.S. immigration history was Oregon farmer Harry Holt, whose individual efforts to bring children from Korea and Japan (and later from other countries) to adoptive families in America eventually evolved into the licensed agency that we now head. Therefore, it is appropriate to report that insofar as we can determine in retrospect, the proportion of children he placed who had serious enough adjustment problems to require removal from original adoptive homes was about the same as the proportion of children placed by the licensed adoption agencies at that time who had similar problems.

The original intent of proxy arrangements for intercountry adoptions—to provide homes for outcast children fathered by American soldiers—was quickly accepted in Korea. The proxy procedure was also applied to provide homes in the United States for many orphans of full Korean parentage and for large numbers of children from Japan, Italy, and Greece in the 1958–61 period.

An impasse soon developed between American parents determined to adopt children who were victims of the Korean war on the one hand and American and Korean child welfare agencies on

Table 1.—AVERAGE ANNUAL ADMISSIONS OF IMMIGRANT ORPHANS TO THE UNITED STATES FOR ADOPTION, BY REGIONS OF BIRTH AND BY PERIODS, 1948–1970

Region of birth	1948–1957		1958–1961		1962–1968		1969		1970	
	number	*percent*	*number*	*percent*	*number*	*percent*	*number*	*percent*	*number*	*percent*
Europe	561	73	963	39	676	41	549	26	587	24
Asia	206	27	1,436	59	916	56	1,155	56	1,349	56
North America	0	.....	35	2	27	2	312	15	404	17
South America	0	.....	3	.....	3	.....	27	1	33	1
Africa	2	.....	8	.....	8	.....	15	1	16	1
Australia/New Zealand	1	.....	2	.....	11	1	13	1	16	1
All other	2	.....	7	.....	4	.....	9	.....	4	.....
All countries	772	100	2,454	100	1,645	100	2,080	100	2,409	100

Summaries and averages by authors; figures: U.S. Immigration and Naturalization Service.

the other. In general the agencies were not ready to expand intercountry adoption service—a relatively untested procedure—particularly when regulations allowed adoptive American parents to bypass usual screening and other supportive social services. This impasse was resolved by extending the time limits of the Refugee Relief Act for 1 year to 1957.

From 1958 to 1961 the United States experienced its highest number of intercountry adoptions. On September 1, 1957, Congress renewed provisions for immigration of orphan children under visas and extended the time limits for proxy adoptions through 1961. Stimulated by this legislation, almost 11,000 intercountry adoptions were arranged during the 3-year period.

Not all proxy adoptions worked out well, however, and we are fortunate that this phase of our country's adoption practice ended in 1961.

Current legislation

From 1962 to 1968 intercountry adoptions declined under the legislation passed in 1961, which is still in effect. While there have been considerable fluctuations from year to year, this period shows no definable trends in adoptions. Therefore, we believe it constitutes a base of "normal" intercountry adoptive activity under current legislation.

Since 1969 the United States has experienced another dramatic rise in intercountry adoptions. In 1970 such adoptions almost reached the level of the proxy adoption years. (See table 1.) Preliminary figures for 1971 indicate that the increase is continuing.

Table 2 (right) gives comparative figures showing the number of orphan children admitted into the United States in the years 1968 and 1970. The increases have come almost equally from Asia and from North America.

Korea and the Philippines provided most of the increase from Asia. Philippine-American adoptions differ from the normal nonrelative pattern of intercountry adoptions, however: more than 80 percent of the Americans who applied for visas were relatives or stepparents of the Filipino children involved.

In 1968 only two immigrant orphans entered the United States from other North American countries. Two years later the number jumped to 404. The great majority of these children—339—came from Canada, with smaller numbers from Mexico, Jamaica, and Costa Rica. Placements from Canada reflect the growing practice of ignoring State and national boundaries in placing children for whom a home cannot be found in his own community.

The Adoption Resources Exchange of North America (ARENA) is a leader in helping adoption agencies make such placements. Under the direction of the Child Welfare League of America, ARENA maintains a current register of the names of

Table 2.—IMMIGRANT ORPHANS ADMITTED TO THE UNITED STATES IN 1968 AND 1970: A COMPARISON BY REGION OF ORIGIN AND TYPE OF ADOPTION

[Only countries with significant increases shown individually]

Region of birth	1968			1970		
	Total	Adopted Abroad	To be Adopted in U.S.	Total	Adopted Abroad	To be Adopted in U.S.
All countries	1,612	750	862	2,409	981	1,428
Europe	630	393	237	587	356	231
Asia	953	337	616	1,349	365	984
Korea	515	147	368	845	155	690
Philippines	98	18	80	141	14	127
Vietnam	67	2	65	89	11	78
Other	273	170	103	274	185	89
North America	2	1	1	404	199	205
Canada	0	0	0	339	151	188
Mexico	0	0	0	21	21	0
Jamaica	0	0	0	14	4	10
Costa Rica	0	0	0	9	9	0
Other	0	0	0	21	14	7
South America	1	0	1	33	29	4
Colombia	0	0	0	13	12	1
Other	0	0	0	20	17	3
Africa	10	4	6	16	15	1
Ethiopia	0	0	0	9	9	0
Other	0	0	0	7	6	1
Australia/New Zealand	13	12	1	16	14	2
All other	3	3	0	4	3	1

Source: U.S. Immigration and Naturalization Service.

Reaching across barriers of race, culture, and national boundaries . . . a chance for homeless children to belong to a real family.

children who are waiting to be adopted and the names of agency-approved families who are waiting to adopt a child.

The increase in intercountry adoptions of the past 2 years is not a response to an emergency in any one foreign country or region. On the contrary, the number of countries from which the children have come suggests that the reason for the increase is to be found in the United States. The 1968–70 period coincides with a period of increased interest in American-born children of minority races without homes for whom transracial adoptions have been suggested. With the developing shortage of "adoptable" white infants in the United States, American parents are beginning to look overseas for children. Therefore, we believe that intercountry adoptions have now become a permanent part of the American adoption scene.

Service to the child

On the positive side, there is no question that intercountry adoption offers many homeless children of the world their only chance to belong to a real family. The value of intercountry adoption is supported by a growing body of evidence that shows adoption is demonstrably better than institutional life, and that adoption is generally as viable for the child as entry into a home by biological birth.[2-9]

In the emerging countries the new patterns of industrialization break down the extended family system. Yet in the transitional stage, the very mores of blood ties that formerly protected the child now prevent him from being adopted into another home. In other words, the custom of nonrelated adoption is not yet acceptable. Social services are always in short supply, and support for dependent children, relinquishment counseling, and foster homes are non-existent.

Children unfortunate enough to lose their parents and extended family during this stage of national development end up on the streets or in orphanages. In either case, mortality rates are high.

Abandonment of children frequently becomes a problem in developing countries. For example, Korea has had severe problems of adandonment and institutionalization of children since the Korean war. The Korean government has encouraged intercountry adoptions through American and European agencies as part of the answer for children without families. The visibility of intercountry adoptions has impressed Korean adoption agencies, the government, and the people alike with the potential value of intracountry adoption as a preferable alternative to placement in orphanages.

At the beginning of this period, nonrelative adoptions by Koreans were almost unknown. Today such adoptions are gaining popularity. Furthermore, they are being arranged by a growing body of Korean social workers who have become proficient in adoption casework.

Research

Research is needed to evaluate the long-term success of intercountry placements. For more than 20 years, hundreds of children from both European and oriental cultures have been involved in the transfer to homes in other countries. The experience is there; we only lack systematic study for some definitive answers. Placements from Asia that involve not only transcultural but also transracial adjustments are of primary interest now. Their study may provide some clues to guide us in the current effort to meet the needs of American-born children of minority races through transracial adoptions.[10]

Followup studies of transracial and transcultural adoptions, which are still fairly rare, usually comprise reviews of the first few years after placement. Most of these followup studies [11-15] as well as a symposium held on the subject [16, 17] suggest favorable results. For example, during the 1960s David Fanshel studied American Indian children adopted by white families, a practice with many cultural and psychological parallels to intercountry adoption. He found the children are doing "quite well." [18]

A study of placements of Korean children who are now 13 years of age or older and who have been in their homes for 5 to 15 years is underway at the University of Oregon. Preliminary indications are that the great majority of the adolescents and young adults are making satisfactory long-term adjustments.

Problems of adjustment

Although further study of long-term adjustment of intercountry adoptions is needed, we can make some subjective judgments based on our experience. Infants traveling to the United States from abroad usually experience temporary confusion from the trip, but face few cultural or language adjustments. Preschool children face many adjustments in culture and language, but the great majority appear to pass through this transition with no enduring problems.

The adjustment problems with which children and adopting families will need to cope and for which they may need supportive social services appear to increase in somewhat lineal fashion as the child's age at placement increases. Adoption during the years of puberty and the teens is the most difficult. Yet—perhaps somewhat surprisingly—a number of families report successful adjustments of children adopted even during and following puberty. Key factors are the attitudes and adaptability of the teenagers and the resourcefulness and experience of the parents. Agency support during the pre- and post-placement periods is vital for older children as well as for their adopted families.

Identity problems are sometimes heightened by the excessive attention that a family or a community pays to a child of a different race or nationality. At least for oriental children, this seems to be a greater danger than the commonly discussed one of racial rejection. Our impression is that in a supportive home the problem of identity is no different for adopted Asian children than for children of American businessmen or missionaries returning to the States after living abroad. Furthermore, the issue of identity for the immigrant child in the United States must be balanced against the alternative problems of identity and self-worth within an institution in the country of his birth.

Benefits and risks to the family

The motivations of families undertaking an intercountry adoption seem to be undergoing change. Initially such adoptions represented a concern for displaced children following the devastation of a world war. Today parents interested in intercountry adoptions show a more general awareness of the problems of children throughout the world and a concern about overpopulation.

Although some families turn to intercountry adoption when unable to adopt a child in their own community or State, many others make intercountry adoption their first choice. By intercountry adoption they seek to experience a common humanity across the somewhat artificial, yet frequently painful, barriers of race, culture, and national boundaries. Such motivations may reflect healthy humanitarianism or they may have some basis in feelings of guilt. Likewise the motivation for adopting a GI child of part-American parentage may be based on guilt, on racial prejudice, or on racial openness.

The adopting family, with help from the child welfare agency, must work through these feelings to discover its true motivation for seeking the child.

As long as the drive to have and to raise children continues, adoption will benefit participating families—particularly those in which the parents are unable to have children biologically—as well as the children themselves. All adoptions provide an opportunity for a parent-child relationship that may be second only to marriage in terms of human intimacy.

The risks for the family in an intercountry adoption are inherently the same as those in an adoption of a child from the community or State. Early deprivation in many cases retards the child's physical and mental development. Although the physical recovery of the child in an adopted home can be dramatic and gratifying, the long-range mental effects are not as easy to assess. However, there is now reason to believe that the effects of early deprivation are more easily reversible than we once thought.[19]

In our experience, children who have survived particularly grim circumstances frequently show unusual strengths and drives that lead them to excel after adoption. It is important, therefore, that adoptive families be positive in their acceptance of the child and flexible in their expectations of academic, social, and athletic achievements.

Medical and social services for a homeless child in a developing country do not equal those available to adoptive parents in a developed country. Thus, the incidence of arrested tuberculosis and infections in children from other countries is higher than in American-born adopted children. The problems of communication

occasionally prevent the discovery of a health problem until the child arrives in the United States.

The role of the agency

American adoption agencies have played a significant role in the increase in intercountry adoptions since 1968. Figures from the Immigration and Naturalization Service given in table 2 include a breakdown between the children adopted abroad by American citizens and then brought back to this country, and the children for whom adoption will be completed after their admission into the United States under a visa obtained by citizens who have met preadoption requirements through an agency in the United States. With minor exceptions, therefore, the column marked "to be adopted in U.S." indicates the involvement of U.S. adoption agencies. From 1968 to 1970 intercountry placements by U.S. agencies increased 65 percent while overseas adoptions increased 31 percent.

The placing of a child through intercountry adoption represents a considered judgment on the part of the agency that an adoptive home will serve the best interests of the child and is preferable to the other options available to that child. When such a judgment is made, the adoption agency must be willing to take some calculated risks in behalf of the child and his family.

Since both the child and the family assume additional risks and adjustments in intercountry adoption not present in intracountry adoption, the normal screening, counseling, and supportive roles of the adoption agency are particularly important. The family can be helped immeasurably by an explanation and interpretation of the circumstances out of which the child came and by a joint exploration with the agency staff of each member's own attitudes, expectations, and resources.

Once the decision to place a child with a specific family has been made, the adoption agency should assume the role of expediter. While regulations governing intercountry adoptions provide valuable safeguards for the child, they can add up to time-consuming formalities. Therefore, an American adoption agency can perform a real service by assisting the family in preparing the necessary supporting documents and in avoiding other unnecessary delays.

American social agencies need to verify the fact that the adoptive family does indeed have adequate resources. The corresponding agency overseas wants assurance that the child is entering an adequate family and will receive full legal adoption, including inheritance rights, legal rights, and citizenship. Some countries have a form of "adoption" that omits one or more of these elements. Some other countries have a practice of "adoption" that really constitutes a labor contract: a middle- or upper-class family "adopts" a girl from a poor family and promises to educate her to some degree while in return she becomes a concubine or housekeeper-child nurse.

A major problem in intercountry adoptions is the lack of compatibility between legal systems of different nations. The area of adoptive law appears to be the slowest to respond to the changing concepts of child welfare needs. Some major developing countries do not even have a basic child welfare law.

Agencies involved in intercountry adoptions have an opportunity to urge upon governments reforms that may be needed in laws and procedures. For instance, a number of developing countries quite understandably insist on a completed legal adoption under their own laws before permitting a child to leave to join parents in another country, in the belief that this is the most concrete protection they can offer the child. We believe the advantages of a trial placement and the reliance on responsible adoption agencies for support as alternatives to the present procedures should be advocated by agencies dealing with authorities in these countries.

An adoption agency can accomplish a great deal through public education. Many parents' groups have organized recently in the United States with the express purpose of facilitating adoptions. The interest of such groups can be utilized to publicize the needs of homeless children in the United States and abroad, to encourage an interest in assisting all children by the best means available, and to support progressive child welfare legislation.

Agency staff members must work through their own philosophy and the motivations of adopting parents to be certain that intercountry placements are made on the basis of humanitarian service to the child and the family. Economic reasons are a poor basis of motivation because they imply a rejection of the child's cultural heritage.

We believe in encouraging parents to study the culture from which their adoptive child comes and so impart to him a pride in the country of his birth. It is healthy to recognize the reality of differences in race, nationality, and culture, just as it is healthy to

recognize that parenting by adoption is different from parenting by birth.[20, 21]

World view

The world child welfare situation as well as the practice of intercountry adoptions would be strengthened immeasurably by bringing some uniformity and modernization to adoption laws throughout the world. The European Convention on Adoption of Children in 1967 has had a beneficial influence on the updating of European adoption laws. The World Congress on Adoption and Foster Placement in Milan, Italy, in September 1971 petitioned the United Nations to convene an international conference for the purpose of establishing a World Convention on Adoption Law.

Intercountry adoption is a difficult concept for a developing country. The country gives an implicit acknowledgment in allowing such adoptions that it is not able to care adequately for its homeless children. The situation represents a reversal of the usual course of giving from the developed to the underdeveloped country. The underdeveloped country gives its children—its most valuable possession—to the developed country. The process demands sensitivity, mutual respect, and a high level of trust on the part of the responsible people in each country.

There is a danger that intercountry adoption, which concentrates a lot of money and assistance on a few children who are taken out of the country of their birth, will become a substitute for material aid, improved nutrition, better education, and the whole range of family services needed for large numbers of children within a developing country. Our experience in Korea, however, suggests the reverse to be true: intercountry adoptions have stimulated local services to children.

The personal interest that adoptive parents take in their child's background and heritage often leads to a personal interest in and support of voluntary work in the developing country and, as a corrollary, increased public support for assistance by private and governmental agencies.

We believe the practice of intercountry adoption in the United States has come of age. The broad participation of American adoption agencies opens up the possibility of an exciting new humanitarian people-to-people social service and mutual social development through the practice of intercountry adoptions.

The ultimate goal should not be limited to helping the few children who may benefit directly from intercountry adoption, but should be to encompass the welfare of every child in the world who needs service.

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[1] P.L. 85–316, September 26, 1961.

[2] Skeels, H. M.: Children with inferior social histories; their mental development in adoptive homes, *Journal of Genetic Psychology*, Volume 72, 1948.

[3] ————: Effects of adoption on children from institutions. *Children*, January–February 1965.

[4] Kadushin, Alfred: Adoptive parenthood: a hazardous adventure? *Social Work*, November 1966.

[5] Morrison, Hazel: 1950 research study in adoption program, *Child Welfare*, July 1950.

[6] Edwards, M. E.: Failure and success in the adoption of toddlers. *Case Conference*, November 1954.

[7] Pringle, M. L. Kellmer: Adoption—facts and fallacies. Longmans, Green & Co. Ltd., London, England. 1967.

[8] Davis, Ruth M.; Douck, Polly: Crucial importance of adoption home study. *Child Welfare*, March 1955.

[9] Witmer, Helen; Herzog, Elizabeth; Weinstein, Eugenie; Sullivan, Margaret E.: Independent adoptions—a follow-up study. Russell Sage Foundation, New York, N.Y. 1963.

[10] Gallagher, Ursula M.: Adoption resources for black children. *Children*, March–April 1971.

[11] DiVirgilia, L.: Adjustment of foreign children in their adoptive homes. *Child Welfare*, November 1956.

[12] Welter, Marianne: Comparison of adopted older foreign and American children. International Social Service, New York, N.Y. 1966.

[13] O'Conner, Louis, Jr.: The adjustment of a group of Korean and Korean-American children adopted by couples in the United States. MSW thesis, University of Tennessee, Knoxville, Tenn. June 1964.

[14] Keltie, Patricia Emilie: The adjustment of Korean children adopted by couples in the Chicago area. MSW thesis, Jane Addams Graduate School of Social Work, University of Illinois, Chicago, Ill. 1969.

[15] Kim, Hi Taik; Reid, Elaine: After a long journey. MSW thesis, School of Social Work, University of Minnesota, Minneapolis, Minn. June 1970.

[16] Pettiss, Susan T.: Cultural factors in adoption of immigrant children. *Social Work*, July 1962.

[17] Adoption of oriental children by American white families. (Edited transcript of symposium sponsored by International Social Service.) Child Welfare League of America, New York, N.Y. 1960.

[18] Fanshel, David: Far from the reservation: the tranracial adoption of American Indian children. Child Welfare League of America, New York, N.Y. 1971.

[19] Rathburn, Constance; McLaughlin, Helen; Bennett, Chester; Garland, James: Later adjustments of children following radical separation from family and culture. *American Journal of Orthopsychiatry*, Volume 28, 1958.

[20] Kirk, H. David: Shared fate, Glencoe Free-Press, Montreal, Quebec, Canada. 1964.

[21] Toussieng, Paul: Realizing the potential in adoptions. *Child Welfare*, June 1971.

PROGRESS IN EARLY DIAGNOSIS OF SICKLE CELL DISEASE

Howard A. Pearson

In his health message to Congress on February 18, 1971, President Richard Nixon called for the allocation of $6 million for research and treatment of sickle cell anemia. Doubtless his statement was the first time that many Americans had heard the name of the severe and incapacitating blood disease that affects about one in every 500 black babies born in the United States each year. Even within the black communities of this country, there has been little dissemination of information about this condition and its hereditary aspects.

Sickle cell anemia was first recognized in Chicago 60 years ago by a physician named James Herrick. During an examination of the blood of a young West Indian student, the doctor observed many red blood cells that were elongated and pointed instead of round. Dr. Herrick compared these abnormal forms to the blade of a sickle, and coined the term "sickle cell anemia" to describe the disease.[1]

In the ensuing years a characteristic picture of sickle cell anemia has developed. It is an inherited disease that affects black people almost exclusively. Accompanied by severe anemia and by recurrent painful episodes called "crises," the disease markedly reduces life expectancy. It is unusual for a person with the disease to live beyond the third decade, and indeed many die during infancy and childhood. Estimates indicate that as many as 25,000 black people in the United States may have sickle cell anemia; thus the disease occurs at least as frequently as such highly publicized scourges of children as muscular dystrophy and hemophilia and more frequently than phenylketonuria (PKU).

Since sickle cell anemia is not curable, early recognition of the disease is vital to proper management of the affected child. Reliable techniques have recently been developed for diagnosing the disease in newborn babies. When parents are told about a diagnosis of sickle cell anemia in a very young child, they can try to avoid many conditions that may lead to crises and make sure that the child obtains medical attention as soon as symptoms or severe complications appear.

Other new diagnostic techniques permit the screening of large populations of blacks to identify persons who do not have the disease but who may be at genetic risk.

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Basis of the disease

Normal blood cells get their red color from hemoglobin, an iron-containing protein that transports oxygen from the lungs to the tissues of the body. Most people have a type called adult hemoglobin, or hemoglobin A. In contrast, virtually all of the hemoglobin in the red cells of persons with sickle cell anemia is an abnormal type called sickle hemoglobin or hemoglobin S.

The chemical difference between hemoglobin A and hemoglobin S was first demonstrated by Linus Pauling and his associates in 1949. Because an abnormal type of protein molecule was involved, Pauling designated sickle cell anemia as a "molecular disease."[2]

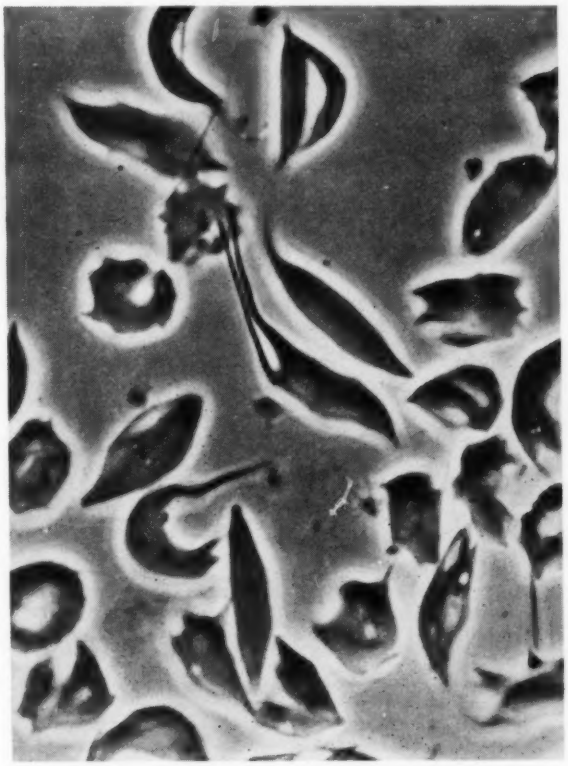
Many other hemoglobin types have also been detected. Fetuses and young babies have a type known as fetal hemoglobin, or hemoglobin F. Hemoglobin C occurs in about 3 percent of the black population of the United States and hemoglobin E is prevalent in Southern Asia.

When hemoglobin S is deprived of oxygen, it forms elongated, pointed crystals. The sickled red blood cell, a manifestation of this crystalization, is visible through a microscope. (See photomicrograph, p. 223.) In a person with sickle cell anemia, sickled red cells often form spontaneously during venous circulation when the red blood cells give up oxygen to the tissues. The body acts quickly to remove these

abnormal sickled cells from the bloodstream, and a severe degree of anemia ensues. In addition, the pointed elongated cells may obstruct the flow of blood through small blood vessels, resulting in the damage or death of tissues. This tissue damage is the basis of the sickle cell crises.

Blood vessels in virtually every organ and tissue of the body may be involved by this kind of obstructive process; symptoms during crises vary according to the location of the blocked blood vessel. In infancy the hands and feet are often involved, producing painful swelling (hand-foot syndrome). In later life the arms, legs, and abdomen are frequently affected, causing pain that may be incapacitatingly severe. Strokes and blindness result from involvement of the vessels of the brain and eye. Obstruction of vessels in the lung brings episodes of severe chest pain and difficulty in breathing. Because of the many symptoms associated with the disease, sickle cell anemia has been described as a "great imitator."

At present, there is no cure for sickle cell anemia or even a completely satisfactory treatment for its crises. Because crises may be precipitated by dehydration or infection, good health management calls for anticipating these conditions and preventing them when possible; when crises develop, they should be treated vigorously.



Contrasting with the roundness of normal cells are the pointed, elongated shapes of the red blood cells shown in this photomicrograph, which has been magnified about 1,000 times. The malformed cells are characteristic of sickle cell anemia, an inherited blood disease.

During severe crises the patient frequently must be hospitalized for intravenous fluid therapy and relief of pain. Blood transfusions are occasionally used for severe anemia, but the value is only temporary.

A large number of drugs and treatments have been proposed over the years. However, most have been found to be ineffective when subjected to controlled clinical trials. Recently a great deal of attention has been given to preliminary reports of possible beneficial effects of intravenous infusions of large doses of urea for the sickle cell crisis, but this treatment is still experimental. Risks are associated with the infusion of large amounts of urea, so it is not recommended for small children.

Genetics

The production of hemoglobin is a genetically determined, inherited mechanism. Every person possesses a pair of genes that govern the synthesis of hemoglobin. One gene is inherited from each parent.

When both parents transmit the normal gene that results in the presence of hemoglobin A in the red cells, the child does not have sickle cell anemia.

The production of hemoglobin S is governed by an abnormal, mutant gene. When each parent gives the child one abnormal gene, virtually all the hemoglobin within his red cells is hemoglobin S. The child thus inherits sickle cell anemia. The person with sickle cell anemia also passes the sickle cell gene to his children. However, because fertility is often impaired in this disease and because of a short life span, many victims do not have children.

Some people—including the parents of children with sickle cell anemia—have red cells that contain a mixture of hemoglobin A and hemoglobin S. Because they have one gene for hemoglobin S and one gene for hemoglobin A, such people are said to have sickle cell trait. This trait occurs in 6 to 8 percent of black people in the United States.

In a person with sickle cell trait, 35 to 40 percent of hemoglobin in the red blood cells is the abnormal hemoglobin S. Spontaneous sickling does not occur in the circulation because the red cells contain enough normal hemoglobin A to counteract the effects of the hemoglobin S. There is no disease or anemia associated with sickle cell trait, and the trait does not

affect life expectancy or fertility. In fact, an affected person probably never knows that he has the sickle cell trait and is a carrier of the sickle gene unless special blood tests are conducted.

Medical reports have described abnormal symptoms in a few persons with sickle cell trait. Most of these incidents have been associated with a marked reduction of oxygen. For example, a few persons with sickle cell trait have experienced abdominal pain when flying in unpressurized airplanes at high altitudes as a result of sickling in their spleens. However, modern air travel imposes no hazard for the person with sickle cell trait. At the present time there is no evidence that the person with sickle cell trait must modify his ordinary life style in any special way. It should be emphasized that the person with sickle cell trait should consider himself normal.

The reason that sickle cell anemia and sickle cell trait are particularly prevalent in the black race may be explained briefly. The sickle gene is believed to have arisen by spontaneous mutation thousands of years ago in equatorial Africa. It has been convincingly demonstrated that the person with sickle cell trait has an enhanced resistance to infection by the malaria parasite.[5] This resistance markedly increases survival in malarious areas, resulting in natural selection for persons with sickle cell trait. In some parts of Western Africa where malaria is endemic, the sickle cell trait is found in 40 percent of the population. In the United States and other areas where malaria has been eradicated, sickle cell trait is no longer an advantage.

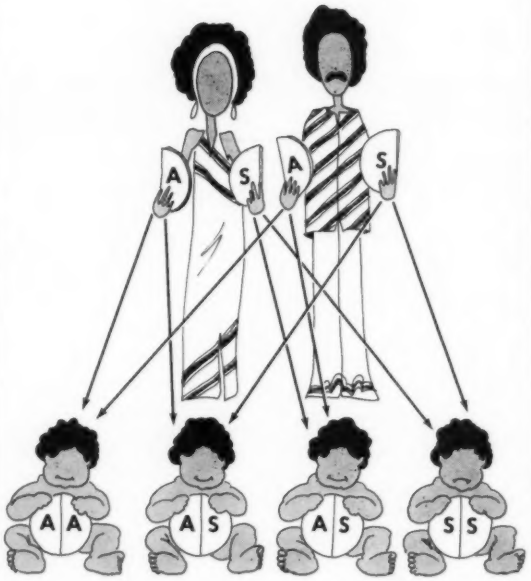
The distribution of the sickle gene outside of Africa to other parts of the world can be largely explained by the slave trade during the 16th to the 18th centuries. Nevertheless, the gene is not restricted to those of African ancestry. A small number of persons of Italian, Greek, near Eastern, and Indian descent have also been found to have typical sickle cell trait.

Another molecular disease, hemoglobin S–C disease, is also the result of abnormal hemoglobin. Although hemoglobin C is almost half as frequent as hemoglobin S in blacks, the person with hemoglobin C trait seldom knows of his condition because he has absolutely no symptoms. When a person inherits a gene for both hemoglobin C and hemoglobin S, he develops hemoglobin S–C disease. This condition resembles sickle cell anemia, but is usually not as severe.

Sickle cell trait and sickle cell anemia—collectively known as sickle cell disease—can be diagnosed by several methods. A number of screening tests detect the presence of hemoglobin S within red cells. Such tests require only small amounts of blood that can be obtained from a finger stick, so they are practical for population surveys. One screening test, the sickle cell preparation, has been widely used in the past.[4] In this test, blood cells are exposed to a chemical reducing agent. When the red cells being tested contain hemoglobin S, they assume a crescent or sickle shape that can be observed under the microscope. This test is inexpensive, but it has a significant number of false negative results.

A second screening procedure is called the Sickle-

HOW PARENTS TRANSMIT SICKLE CELL DISEASE



Parents who are carriers of the sickle cell trait do not show symptoms of the disease because hemoglobin A (the normal form of hemoglobin) in their red blood cells protects them from hemoglobin S (the sickling form). But when two carriers become parents, the possibilities are:

- One child in four will inherit all normal hemoglobin (AA) and thus be free of the disease.
- Two children in four will inherit both hemoglobin A and hemoglobin S (AS) and thus become carriers of the trait like their parents.
- One child in four will inherit all sickling hemoglobin (SS) and thus become a victim of sickle cell anemia.

dex test.[5] In this test, a small amount of blood is introduced into a solution of buffered salt containing a chemical reducing agent. When the red cells being tested contain hemoglobin S, the solution becomes cloudy; when only hemoglobin A is present, the solution remains clear. The Sickledex test is simple and fast, and it can be performed by health aides and volunteers who do not have technical training. However, it is relatively expensive.

The utility of the Sickledex test under field conditions was recently demonstrated by a screening program in the Hartford, Conn., public schools. A total of 3,456 students were tested, and the blood of 301 of these children was found to be positive for hemoglobin S.[6]

A major disadvantage of these screening tests is that they do not distinguish precisely between persons with sickle cell trait and sickle cell anemia. Therefore, more definitive confirmation is necessary for persons with positive tests. In addition, these screening tests do not detect other abnormal hemoglobins that occur in the black population with important genetic implications.

Specific diagnostic tests for abnormal hemoglobins employ a technique called hemoglobin electrophoresis. In this method, a small amount of hemoglobin prepared from red cells is subjected to an electrical current on a medium such as filter paper or gel. Under these conditions hemoglobin, which has a negative electric charge, is attracted toward the positive pole of the current. Because hemoglobin S has a slightly different charge from hemoglobin A, the two hemoglobins separate from each other.

A disadvantage of hemoglobin electrophoresis has been that the analysis requires a relatively large amount of blood, which must be drawn from a vein. In the past the procedure itself has been complicated and expensive, and has required services of a medical technologist. These disadvantages have been largely overcome by a technique recently devised by Dr. Marshall Barnes at the Yale-New Haven Hospital.[7] Using cellulose acetate strips for hemoglobin electrophoresis, this technique requires only a small amount of blood. It is reliable and accurate, takes only 30 minutes to complete, and costs about 5 cents per test for materials.

In a recent sickle cell screening program in New London, Conn., we used cellulose acetate strips in analyzing the blood of nearly 700 children. One technologist in our laboratories made 150 hemoglobin electrophoresis assays in 8 hours, showing that this technique can be used to study large populations.

I believe that the development of such definitive, reliable, and utilitarian electrophoretic methods has virtually obviated the need for less reliable and less specific screening methods, such as the Sickledex and the sickle cell preparation tests.

Sickle cell anemia in infancy

Although the disease is inherited, the affected baby shows no signs of sickle cell anemia at birth. This is because all fetuses and young infants have fetal hemoglobin (Hgb F), a type that does not cause the disease. During the months after birth, the hemoglobin F in the affected child's red cells is gradually replaced by hemoglobin S. As the proportion of hemoglobin S increases, the symptoms of anemia appear—usually when the baby is between 6 months and 1 year of age.

There is a particular urgency for early recognition of sickle cell anemia, for the first indication of the disease in an infant may be sudden death from severe infection or anemia. Diagnosis of sickle cell anemia in an infant is technically difficult however, because of the large amount of hemoglobin F in the red cells in the first 6 to 8 months of life. During this time the sickle cell preparation and Sickledex tests are usually negative, and usual methods of electrophoresis are often inconclusive.

At the Yale University School of Medicine, we have been able to diagnose cases of both sickle cell anemia and sickle cell trait at birth by using electrophoresis on a medium of agar gel. The agar gel method makes it possible to clearly distinguish the normal newborn infant from one with sickle cell anemia or sickle cell trait.[8]

Based on this test, we have instituted a program for early detection of sickle cell anemia at Yale-New Haven Hospital. Every pregnant black woman has a hemoglobin electrophoresis performed as part of her prenatal laboratory examination. Since the mother must have sickle cell trait to have a child with sickle cell anemia, blood from the umbilical cord is collected for testing only from infants born of such mothers. After tests are completed, it is possible either to reassure families that there is no problem or to diagnose the disease and alert them to seek medical attention at the first sign of serious anemia or infection.

Need for screening

Children with sickle cell anemia almost always develop symptoms in the first 2 years of life. In localities with good health facilities most cases of sickle

cell anemia are detected by the time affected children are 3 or 4 years old. For example, in an extensive survey of more than 6,000 children 4 to 17 years of age in North Florida several years ago, I did not identify a single previously unrecognized case of sickle cell anemia.

I believe the major rationale for screening procedures after infancy is to identify individuals with sickle cell trait. About one in 12 black persons in the United States has sickle cell trait. Therefore, in approximately one out of every 144 marriages, both partners will have sickle cell trait. On the average, one in four children born of such marriages will have sickle cell anemia. The illustration on page 224 shows the genetic probabilities.

Because there is no cure for sickle cell anemia, prevention offers the only method currently available to avoid the problems inherent in having a child with the disease. In my opinion the major aim of screening programs is to identify persons with sickle cell trait so that they can be informed about the genetic implications. Each carrier should know that if he marries another person with sickle cell trait, their children may have sickle cell anemia.

Screening programs must incorporate meaningful education about the nature of sickle cell anemia and its mode of inheritance, as well as individual counseling. Information about sickle cell disease could be easily introduced into the science and biology curricula of the schools. Certainly sickle cell anemia and trait offer a more relevant illustration of genetic principles than fruit flies or peas!

The ideal timing for testing programs has not been determined. If the aim of testing is to provide carriers of the sickle cell trait with information applicable to marriage, testing in infancy or early childhood may be too early. The teens would seem to be a particularly advantageous age. A junior or senior high school student is usually receptive to a sickle cell educational program when he learns the results may have personal relevance; he also is accessible for testing and counseling. A number of programs designed for teenagers have been well received.

Study of hemoglobin could be incorporated in the premarital blood test, but by this time the results would probably be too late to affect the couple's decision to marry.

It is my belief that the purpose of testing programs is to provide individuals and couples who carry the sickle trait with the information they need to make personal decisions about marriage and childbearing. Most people would not knowingly bring a child into the world with a painful and incurable disease that has major emotional and financial burdens.

Only by widespread implementation of programs of testing and education can the people at risk be given the information they need for informed decisions. Time will tell whether this approach has validity or merit.

Future prospects

Despite development of detailed and sophisticated information about the genetic basis and molecular biology of sickle cell anemia, the treatment of the affected child himself is still imperfect. It is necessarily directed to alleviating pain and symptoms, not to curing the disease. Nevertheless, experienced physicians trained in pediatrics and hematology can do much to help these children by skillfull management of crises and anticipation of complications. Regional centers for the treatment of and research on sickle cell anemia would doubtless improve clinical care and prognosis. A painstaking search for chemicals and drugs to inhibit the sickling process within red cells should be continued.

For the future I believe that the most promising experimental possibility for the cure of sickle cell anemia resides in the area of bone marrow transplantation. Since anemia, organ dysfunction, and crises are all a consequence of spontaneous sickling of red cells in the circulation, transplantation of normal bone marrow and the subsequent production of normal red cells should reverse all aspects of the disease. Although bone marrow transplantation is not possible today, basic research into the immunologic problems of tissue typing and compatibility and the principles of organ transplantation and immune rejection may some day enable this terrible disease to be cured.

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[1] Herrick, J. B.: Peculiar elongated and sickle shaped red corpuscles in a case of severe anemia. *Archives of Internal Medicine,* November 1910.

[2] Pauling, L.; Itano, H. A.; Singer, S. J.; Wells, I. C.: Sickle cell anemia: a molecular disease. *Science,* November 25, 1949.

[3] Motulsky, A. G.: Hereditary red cell traits and malaria. *American Journal of Tropical Medicine and Hygiene,* January 1964, supplement, part 2.

[4] Daland, G. A.; Castle, W. B.: A simple and rapid method for demonstrating sickling of the red blood cells. The use of reducing agents. *Journal of Laboratory and Clinical Medicine,* September 1948.

[5] Ballard, M. S.; Radel, E.; Sakhadeo, S.; Schorr, J. B.: A new diagnostic test for hemoglobin S. *Journal of Pediatrics,* January 1970.

[6] Bellizzi, J. J.; Conley, H. D.: Report of the Hartford Schools sickle cell test programs, March 1971. Personal communication.

[7] Barnes, M. G.; Komarmy, L.; Novack, A. H.: A comprehensive screening program for hemoglobinopathies. *JAMA* (in press).

[8] Pearson, H. A.: Hemoglobin synthesis in the fetus and newborn: diagnosis of congenital disturbances of hemoglobin metabolism. *In* The clinical pathology of infancy. Sunderman, F. W., and Sunderman, F. W., Jr., editors. Charles C Thomas, Springfield, Ill. 1967.

Caring for Children With Sickle Cell Anemia

Camille L. Duckett

Throughout his life the child with sickle cell anemia faces the possibility of sudden painful crisis episodes that may keep him in the hospital or away from his normal activities for days. In caring for a child in a sickle cell crisis, the focus of the pediatric health team is on the child and his family.

There is as yet no cure and no magic formula for treatment of this wasteful disease of black children. But there are specific approaches to the crises and problems that can be individualized according to the needs of each child, his family, and the setting involved.

Black families have been largely alone in their struggles against sickle cell anemia, an inherited disease with chronic aspects.[1] Although estimates suggest the disease affects 1 in 500 black Americans, no actual survey has been made to accurately define the incidence of sickle cell anemia in the black population. There has been no mobilization of finances, research, and other resources against sickle cell anemia comparable to the nationwide campaigns against phenylketonuria (PKU) and cystic fibrosis. Yet the latter diseases of whites do not affect as large a segment of the population as sickle cell disease—PKU occurring in 1 of 10,000 live white births and cystic fibrosis in 1 of 1,000 to 2,000 live white births.[2]

Fortunately Federal funds have recently been earmarked to support research and to expand the efforts to find a cure. Some support will also go to providing service, which must not be overlooked as part of the sickle cell disease picture.

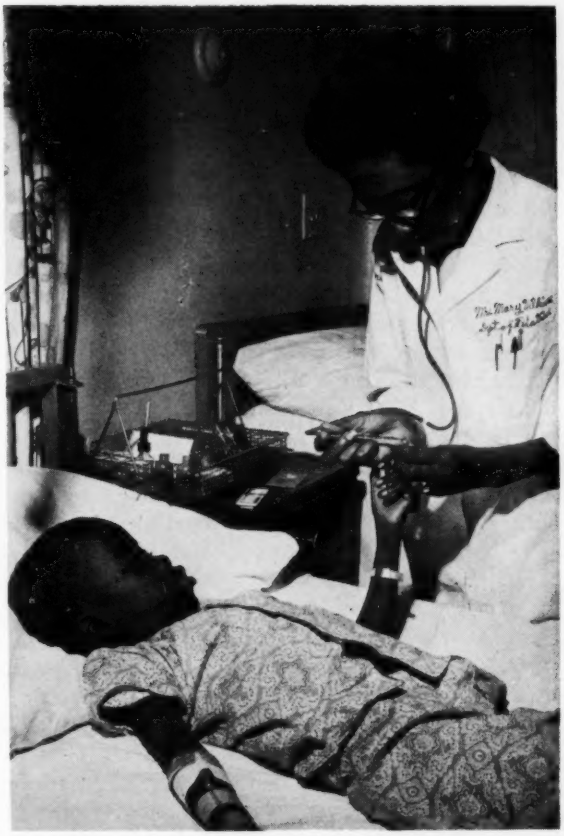
Furthermore, black health professionals and the black community as a whole must be included from the beginning in all planning, research, administration, and service activities related to the disease, since they are directly affected by such programs.

The nurse

As the health professional who is responsible for daily care of the child with sickle cell anemia, the hospital staff nurse has a crucial role to play as a member of the pediatric health team. In examining the nurse's work as it applies to sickle cell anemia, I have drawn on my experience in the Department of Nursing Service and the Department of Pediatrics at Howard University-Freedman's Hospital in Washington, D.C., for a general guide.

I do not intend to imply that the Department of Pediatrics at Freedman's Hospital institutes comprehensive care for every young patient. The work load, environment, and makeup of the comprehensive multidisciplinary team affect the implementation of care for the patient and the interaction of professional and subprofessional health workers.

However, I believe the approaches used at Freedman's Hospital can be as useful to the nurse serving in a physician's office, home, community health



A technician takes blood from a child with sickle cell anemia, a process that is repeated many times during crisis episodes.

agency, and public or parochial school as in the hospital.

The major functions of the hospital staff nurse in relation to sickle cell anemia lie in the following areas:

1. Anticipatory guidance.
2. Coordination and continuity of patient and family care.
3. Health education and casefinding.

Although I see these as major functions in caring for a child with sickle cell anemia, I believe they may also apply to children with other chronic illnesses.

By "anticipatory guidance" I mean the process by which the staff nurse anticipates for parents and interprets to parents the kinds of behavior that can be expected of children with sickle cell anemia at various ages and at various times of stress.[3]

Feelings about the disease

In trying to reach the child and his family, the nurse must first assess the way parents feel about the child's illness. Her impressions of the child's and the parents' reactions to sickle cell disease may change as she meets the family in different settings—the home, clinic, school, doctor's office, or emergency situations—and according to the age of the child and the severity of his condition.

The nurse also must keep in mind that parents often fear censure or reproach by those in authority and, in their effort to gain approval, may hide their feelings or hold back information regarding the child. By phrasing open end questions and restating the parents' comments, the nurse gives them an opportunity to examine their feelings about themselves and the child. She listens calmly, accepting and encouraging the parents to express their negative feelings in order to help them clarify their own thinking.

Health professionals are better able to help a child if they understand some of the family's fears. It is not unusual for children to sense the parents' apprehension about hospitalization. I have found it helpful to ask the parents about their past hospitalizations and talk about their hangups in an attempt to separate their experiences from the child's experience.

A hospitalized child with sickle cell anemia may ask questions that his parents are unprepared to discuss: "Am I going to get well?" "Am I going to die?" Other questions of this type may appear in a disguised form. By telling the parents how to recognize the child's apprehension and encouraging them to let the older child talk about the unpleasant aspects of the disease when he asks unexpected questions, the nurse provides anticipatory guidance that enables the child and the parents to adjust to reality.

The nurse also tries to relieve the child's anxieties about his illness. One way of doing this is to allow the child to explain what is happening to him, and to listen closely to what he says. Role playing of a doctor or a nurse often encourages a child to voice some of his own apprehensions. The young child often expresses his frustrations best through play activities involving finger paints, clay, singing, drawing, dolls, music and noise, and pounding boards.

A child's problems

The child with sickle cell anemia is faced with many of the following problems that the well child does not face:

☐ He has to visit the doctor and go to the hospital frequently.

☐ He takes special medications.

☐ He needs protection from colds, pneumonia, intestinal upsets, and other infections that may precipitate crises.

☐ He suffers from episodes of crisis lasting approximately 1 week and occurring several times a year.

☐ He is thin and small for his age.

☐ He may exhibit feelings of inferiority because of his inability to compete physically with his friends and classmates.

☐ He is frequently absent from school and is sometimes behind his age group.

The nurse can alleviate some fears of the parents of a school-age child by stressing the following positive factors:

☐ Sickle cell disease does not affect intelligence.

☐ Between the crisis episodes the child may join in the usual activities of his age group, with the exception of strenuous sports that result in fatigue. Physicians hold differing opinions about the sports and activities an affected child may safely engage in.

☐ Parents who know in advance that their child may not always be able to participate in strenuous sports can steer him into school, church, and other activities in which he can excel. Activities that may earn the acceptance of friends in his age group include art, painting, handicrafts, debating, composition, chess, checkers, and monopoly.

Through informal counseling the nurse can do a great deal in helping parents recognize and anticipate the needs of a preschool child entering the hospital for treatment of sickle cell anemia for the first

Nurses, a social worker, and a mother make plans for hospital discharge and home care of a child with sickle cell anemia.

time. A child usually reacts to separation from his family in three phases. The first phase is the period of protest; the second, the period of despair; and the third, the period of comfortable adjustment. Parents who have been advised in advance of what reactions to expect can ease the transition of a child from the home to the hospital. For example, the mother may ask the child to help select and pack the items he will need for his hospital stay. Or she may let the child draw a picture of the hospital, the doctor, and a nurse as she tells him what he will experience.

Hospital care

A child admitted repeatedly to the hospital in a sickle cell crisis or other emergency situations requires understanding and emotional support from nurses and parents alike, particularly in terms of previous traumatizing experiences that may have occurred in the hospital. He needs to be reassured that his parents have not rejected him. Parents should be encouraged to visit him regularly and, when possible, participate in his care so he does not feel that they have "given him up" to the hospital.

A child hospitalized in a sickle cell crisis requires the following kinds of medical and nursing care:

1. Administration of medication to relieve pain and antibiotics to control respiratory infections and pneumonia.
2. Administration of oxygen and blood transfusions as indicated.
3. Adequate fluid intake and output.
4. Proper nutrition through the serving of well-balanced meals.
5. Care of the skin, good hygiene, and precautions to avoid bruises and cuts that may lead to infection.
6. Maintenance of proper elimination.
7. Assurance of proper rest.
8. Encouragement of normal exercises and activity after the crisis state has subsided.

During the hospital stay, the health team provides medical and nursing care and the nurse continues to give anticipatory guidance to the child and his family. Since children often have distorted ideas about illness and what is happening to them in a hospital, a simple explanation of the procedures for treating sickle cell anemia should be given frequently to both

the patients and the parents. An older child can be encouraged to write a story about his hospital stay for discussion with parents and hospital staff.

To continue as normal a pattern of daily living as possible for a hospitalized child, numerous hospitals around the Nation have set up special programs to provide diversional activities. Aimed at meeting both the child's psychological and physical needs, the program at Freedman's Hospital is operated by a Recreational Therapy Department within the Department of Pediatrics.

Care between crises

Before a child with sickle cell anemia leaves the hospital, he and his parents need information about how to prevent or minimize crisis episodes. This vital role often falls to the staff nurse, although it may be assumed by any health professional. In counseling parents about the child's activities between the crisis episodes, the nurse may offer the following advice:

☐ Make sure you and the child know how active the doctor wants the child to be. If you do not understand, ask a direct question about what is prohibited.

☐ Do not overindulge the child with toys and gifts.

☐ Treat the child as normally as possible, but set and enforce limits for him.

☐ Answer questions about sickle cell anemia from other children in the family honestly.

☐ Explain the nature of the disease to older children so they will not resent the treatment and special care the child with sickle cell anemia needs. Usually older children welcome an opportunity to be taken into the parents' confidence.

☐ Serve well-balanced meals selected from the basic four food groups. Encourage frequent small meals when the child's appetite is poor and supplement the diet with milkshakes.

Other workers

I will not attempt to describe the team process by which professional and subprofessional health workers interrelate with each other, the young patient, and his family. However, I will describe briefly some of the team members at Freedman's Hospital and their roles in caring for the child with sickle cell anemia.

In addition to the physician and the staff nurse, the dietitian, child psychiatrist, social worker, public health nurse, physical therapist, and speech therapist are members of the pediatric health team. The teacher and the school nurse often assist the team.

The dietitian plays a key role in interpreting the dietary needs of the child with sickle cell anemia to his family. In an informal discussion with the mother, she suggests ways of making liver and greens appetizing, but points out that the child should not be forced to eat liver or any other food. After the mother and the dietitian review the basic four food groups and discuss selection of foods to meet the nutritional needs of the child, the dietitian encourages the mother to serve basic foods to the entire family. Frequently mothers ask the dietitian to recommend foods that can be substituted or exchanged for those in a special diet. The dietitian also reports to the health team about nutritional problems.

The child psychiatrist provides individual counseling to the parents upon request, and explains the effects of sickle cell anemia on child behavior, growth, and development.

The social worker cooperates with the physician, hospital staff nurse, and public health nurse in planning and coordinating activities related to discharge of the young patient. Other major activities of the social worker include evaluating family relationships, assessing the parents' acceptance and understanding of sickle cell anemia, determining the financial impact of the illness on the family, and assessing and interpreting to the health team the behavior of families with psycho-social problems that may effect the adjustment of the patient to his illness. The social worker also coordinates hospital social services with those of community agencies.

The hospital-based public health nurse and the community-based public health nurse complement each other in planning with the parents prior to and following the child's discharge from the hospital. Cooperatively or individually they evaluate the family's ability to meet the needs of the child, assess available nursing care, health information, and provisions for meeting related needs of the child and his family, and assist parents in understanding and accepting the illness. They also report verbally and in writing their observations and assessments of the family to the pediatric team so followup medical and nursing care can be planned after the child returns home. By coordinating and providing liaison activities, these nurses promote continuity of care to the patient and family before and after the child's discharge from the hospital.

The physical therapist serves as a consultant on the pediatric health team. Among other services, she assesses the child's functional ability, strength, and mobility, and plans for the physical therapy. This

includes interpreting physical therapy needs to the members of the health team, particularly to the public health nurse, who is available to direct the family in carrying out recommendations.

The speech therapist also serves as a consultant to the health team. He evaluates the child's speech and language disorders and develops a treatment plan. Assessments are made periodically to determine progress and necessary modifications in the plan. In addition, the speech therapist explains the child's speech and language needs to the family.

Although not technically a member of the health care team, the school teacher who understands sickle cell disease obviously is better able to help the child and his family. The school teacher must try to protect the child from drafts in the classroom and exposure to colds and other infections that may precipitate a crisis. She needs to be aware of the signs of an impending crisis. These include complaints of pain in the back, arms, hands, feet, legs, or the abdomen; the appearance of a slightly yellow hue to the whites of the eye; and listlessness.

The child may have prolonged periods of absenteeism from school due to a sickle cell crisis. Therefore, the school teacher must be supportive to the child and family in regard to his school work and the chronic nature of his illness.

The school nurse, the hospital-based public health nurse, and the community public health nurse work cooperatively with the child and his family. The school nurse helps the teacher recognize symptoms of impending crisis and deviations from normal behavior that may be related to the child's illness. The nurse helps school administrators find ways of meeting the needs of children with sickle cell anemia and uses all her contacts with the child, teacher, and family for teaching about health and providing emotional support. Her activities also include regular reports to the health team about the child's school adjustment.

Continuous care

The health team's second major area of involvement in relation to sickle cell anemia is to ensure that the service to the child and his family is both coordinated and continuous. We are all too aware of the gaps in the health care system and the fragmentation and duplication in care and services.

I cannot help but wonder how often the information in the child's health records is transmitted from the private physician's office to the hospital when hospital admission is contemplated. When the child transfers from one school to another, how soon does his health record follow? How well does the hospital plan with the public health agency for discharge and home followup? When information in health records is not transmitted among the various services in the community or utilized by them, the child is the loser.

Education and casefinding

The third area of concern for the health team is health education and casefinding. Surely our nation, with its highly developed communications system, is able to increase the awareness of thousands of black Americans about the disease, its disabling effects and high death rates, and other implications involved in its transmission to children. A nationwide multifaceted program, similar to venereal disease eradication efforts in the 1940s and 1950s, would involve informing the public about the disease itself, screening potential carriers, and counseling families at risk regarding the genetic aspects of sickle cell anemia.

Black mothers should be routinely screened for sickle cell disease in prenatal clinics, and, when the trait is found, given genetic counseling. Every black child admitted to a pediatric unit of a hospital should routinely have the test for sickle cell anemia. In addition, Head Start programs, schools, colleges and health clinics are appropriate sites for screening. Men inducted into the Armed Forces could be screened and given appropriate counseling as part of their physical examinations.

Members of the health team must give parents and young adults up-to-date, valid information regarding the sickle cell trait. In addition to information, health education programs must make available screening for sickle cell disease and genetic counseling so that the affected person is able to act on the facts regarding the inheritance of the disease.

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[1] Scott, Roland B.: A commentary on sickle cell disease. *Journal of the National Medical Association*, January 1971.

[2] Marlow, R. Dorothy; Sellers, Gladys: Textbook of pediatric nursing. (Second edition.) W. B. Saunders Co., Philadelphia, Pa. 1965.

[3] Scott, Roland B.; Kessler, Althea D.: Sickle cell anemia and your child—questions and answers on sickle cell anemia for parents. Department of Pediatrics and Child Health, Howard University College of Medicine, Washington, D.C. Spring 1971.

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TEENAGERS DISCUSS AGE RESTRICTIONS

Cecelia Sudia and Jane Harwood Rea

When Tui, living in a tribal society, proved himself a hunter or performed certain rituals, he was considered to have also proven his manhood. In such presumably simpler societies belonging to far-away places or times, a standard "rite of passage" from youth to adulthood can be noted.

In today's complex, technological world, however, there are no such clearly defined paths to adult status. Confusion about what makes one an adult in a particular situation is reflected in the differing Federal, State and local laws relating to the age at which a boy or girl may be treated as one.

How do teenagers themselves feel about the various age restrictions placed upon their activities?

A survey of 430 high school students conducted by the Children's Bureau in May 1970 shows that they accept some lines of demarkation between youth and adult status. When asked to discuss the age at which a person should be allowed or expected to engage in activities loosely defined as adult, their replies indicated that they expect to acquire adult privileges and responsibilities over a period of several years—but at a somewhat faster rate than is now the case. They also believe that more emphasis should be placed on competence and less on precise age.

The students questioned ranged in age from 15 to 19 and were randomly selected, as in the previous Children's Bureau inquiries, from lists of students enrolled in college preparatory courses in metropolitan areas of the four main regions of the United States (Northeast, South, Midwest, and West). The sons and daughters of fathers whose employment ranged from unskilled jobs to professional and managerial work, over 80 percent of the students were white, and almost one-fifth black.

What were the issues these youngsters considered most important—and why?

First in importance—and by a wide margin—was the issue of eligibility to vote, for the data were collected before the age requirement for voting in all elections had been lowered to 18. Next in importance were age restrictions on movie attendance, followed by age relating to service in the Armed Forces. Age restrictions bearing on jobs, purchase of liquor and cigarettes, school attendance, driving, and access to confidential medical care were also of sufficient importance to prompt considerable comment. Of lesser interest, but still discussed by more than a fourth of the teenagers, were adult status in court, and age in relation to marriage, childbirth, and financial responsibility.

Should there be age limits?

The Youth Reporters indicated that young people today are willing to accept the idea of some age limits, but are very impatient with certain specific limits now in existence, particularly those whose main function is moral protection. As one observed:

"Ironically it is our Federal government who expects our older brothers and boyfriends to fight all the wars, help protect this *our* country, and to help build this country into an even better stronger nation. All of this is what is expected of us but we cannot vote, marry, or even see a movie because we aren't considered adult enough—it's like telling an eighth grader he can't tie his shoe because he's too little!"

Many of the students were relatively conservative while others referred to the issue of age as a matter of relationships with parents. They spoke of the conflicting expectations of adults who seem more interested in seeing young people demonstrate responsibility than they are in extending privileges to them, and of the rigidity engendered when specific ages are used as cut-off points. As one student said:

"Then once again we come back to the first Youth Report—The Generation Gap. If there is no communication between parent

and child then neither will be satisfied by the age limits set on certain things. If kids would only sit down with their parents, talk and LISTEN, maybe an understanding would be reached and many complex questions solved."

In summarizing the responses, two ratings were made for each issue: the number of young people who responded and their opinions on the issue's importance. In general the two lists matched although there were minor variations. For example, although the movie issue was described as relatively unimportant, it was frequently mentioned, while the medical care issue was considered "very important" by the fewer number of students who discussed it.

Replies were received from only 146 students (34 percent), which is considerably less than the number who responded to the previous Children's Bureau questions on subjects of greater interest to them. (See "The Generation Gap in the Eyes of Youth," *Children*, March-April 1970, and "Drug Use Among the Young: As Teenagers See It," *Children*, November-December 1970.)

The complete findings of the report on age restrictions will be published by the Office of Child Development as Youth Reports No. 3. A summary follows.

The inconsistencies of a society that idealizes individual achievement but bases adult status on the attainment of a certain chronological age were pointed out. Youth Reporters were quick to state that age confers neither competence nor maturity—that age is not a measure of adulthood. Others resent the impersonality of a system that is not responsive to individual differences:

". . . the magic age for a person is 21. He is then an adult and has 'arrived'. If so much importance and important matters were not dependent upon this age, I think responsible people would accept and appreciate youth more."

". . . I can't possibly give a cure-all by naming *the* age for everything—everyone matures at a different rate—everyone *is* different. Perhaps this is the problem today—considering the people as a blob ('silent majority', 'the masses', etc.) instead of as individuals."

Many teenagers claimed that their competence has been increased by the type or level of education they are receiving and believe that the statutory limits should be reduced in whole or in part because of this greater competence. As one put it:

"The pace of education is constantly increasing. I and my friends can look at our younger brothers and sisters and say, 'I never learned things that advanced when I was his age', just as our older brothers and sisters say the same things about us. Just from this personal experience we can see the rapid changes."

"Everyone matures at a different rate—everyone is different."

The students recognized that performing "adult" behaviors before one has attained the legal age enables one to *appear* adult. They rarely accepted the rationale which justifies many age restrictions as protection for young people who are too immature to exercise judgment, or who might be exploited by parents or other adults.

Voting

Youth Reporters definitely feel they are competent to assume voting responsibilities and indicated that their education has been important in preparing them for this role. They believe they have the qualifications necessary to understand the issues and to responsibly exercise the right to vote. "We are better informed than our parents were."

Some of the Reporters indicated an undercurrent of scepticism regarding the actual value of enfranchisement. One noted:

"A part of our learning, emphasized slightly every 2 years and heavily every 4, is the power and responsibility of the voter. At the same time this emphasis is felt, the contradiction of the teaching appears: men, unfit for office because of actions or incompetency, are elected again and yet again, and proposals designed to better lives . . . are defeated."

Service in the Armed Forces

Service in the Armed Forces is of interest to this generation of high school youth, because their age group is very personally involved, and also because it is a subject of considerable discussion in the country as a whole. Age was not the important issue, however. In effect, the students used the question on age as an opportunity to sound off on their attitudes toward the war in Vietnam or the draft as an institution. While a minority (11 percent) indicated a willingness to support the present system, this support seemed unenthusiastic.

Twenty-nine percent recommended that the age for service be higher. "Draft only those over 50" or "not before 21, if that's when you can vote." Several mentioned that service should be after college, or after education is completed. "No teenager should be drafted nor allowed to volunteer."

"A person of 25 has more experience with life's problems and is more capable of doing a better job on the battlefield than an 18- or 19-year-old who may easily become panic stricken in the face of danger," explained one teenager.

It is particularly notable that military service is the only issue on which a sizable number of students suggested an older age requirement and invoked the argument that youth needs protection. This presents a considerable contrast to the strong feelings on almost all other issues—that age limitations should be lower, not higher.

Movie restrictions

More than 85 percent of the young people who commented on this issue are opposed to the present system of restricting movie attendance of teenagers, rejecting it as unacceptable, ridiculous, and easily evaded. This is the highest negative response received.

Teenagers pointed out that they are limited in the number of places they can go and that consequently movies are a popular form of recreation. Therefore, they must regularly contend with a code that is set up for their protection, yet seems to outrage their growing sense of autonomy, encouraging them to lie or otherwise seek to evade the regulation, and perhaps prompting them to hold cynical views about regulations in general.

The largest proportion of students, a little less than half, said there should be no restrictions.

"Kids already know about sex; it's the *adults* who flock to X movies," one student asserted.

"As far as attending any movie, I think that it is ridiculous to set up arbitrary age limits and, in effect, say to a person, 'you are not mature enough now to see this picture, even though in 3 weeks you will be 17 and magically you will suddenly gain the necessary maturity.' I know several 18-year-olds whose maturity would be severely taxed by a Donald Duck cartoon. Age is not the criterion; it is the person's faculty to objectively and intelligently observe and interpret what is happening on the screen that is important," said another.

Or again:

"There is one item that really bothers me, however; the idea of movie censorship. I see this as illegal, and an intrusion into my personal affairs by 'Big Brother.' I don't appreciate having to lie in order to see the best movie of the year."

Another sizable proportion of youth, almost one-fourth, remarked that the code is irrelevant because it isn't enforced.

"It seems to me that some people place a rating or restriction on a movie to put their own morals to rest."

Some students suggested that pictures be given ratings but that the decision on who should attend be a matter of personal choice of the young person alone or jointly with his parents.

Jobs

Most of the Youth Reporters apparently see the age restrictions on job-seeking as somewhat arbitrary infringements on the rights of young people, while a very few recognize the protective rationale behind them:

"If there were no age limit, I think many parents would force their children to work at a very young age."

While the students feel that age limitations on obtaining a regular job should be lower and more flexible ("should depend on competence, not age,"—nor "on hair"), the main problem seems to be the availability of jobs for young and relatively inexperienced workers:

"It is virtually impossible for someone under the age of 18 to obtain a regular job. There are some part-time jobs available, but not many. Many businessmen are afraid to hire young people because they feel they are irresponsible. Storekeepers refuse to accept the responsibility for minors."

Driving

Most of the panel supported the present age for acquiring a driver's license in their respective States, but feel that the emphasis should be on competence, not age.

"The age when a person is capable of driving a car is very flexible. It completely depends on how mature they are, not whether they can reach the pedals."

Some mentioned the difficulties and expenses involved in owning a car and there were also complaints about the "ridiculously high insurance rates" for teenage drivers.

Generally speaking, however, the students did not place great stress upon the matter. The responses might have been more concerned if most students queried had been younger.

School-leaving age

Since the high school students queried were almost entirely college-bound, few were interested in the question of the minimum age at which they could leave school and most feel that it is desirable to continue schooling as

long as possible. Nevertheless, some see a need for a more flexible system of education. They believe that the school-leaving age should be more a matter for individual decision and that re-entry into school should also be possible without penalty. They are of the opinion that those students who are miserable in school and rebel against any form of teaching are "causing more harm than good" and should not be required to stay in school. One suggested:

"For these people, a rule should be set up where they are allowed to leave school when they feel like it and give themselves a shot with life on the outside world. If they find they can't do it, they could always come back to school. Once they see that it is difficult to make it without an education, perhaps they would work harder than anyone in school to see that they got through."

Several Reporters also emphasized that the way should be open for students to change their minds after leaving. They suggested that dropouts should be allowed to return to regular classes if they wish, and not be relegated to adult education programs, or to night school. Explained one teenager:

"I know very well at least five intelligent people who have decided to leave home and school for several months. When they return, they have a large and unfair disadvantage in that they are placed in the local continuation school. If high school were optional, they could have resumed their place without being put in a stifling atmosphere that insures a dropout in a capable student."

More than 40 percent of the Reporters expressed the view that the present age for leaving school (usually 16) is acceptable. Almost as large a group feel that the age for leaving school should be advanced since one "needs all the education he can get." As one said:

"The law is trying to protect people from themselves. In many states children must attend school until they are 16. In this way, people won't make the mistake of dropping out."

Slightly over a tenth of those commenting on this issue feel that the age should be lower: It "should be optional after the ninth grade" or at age 14 or 15, for "if they don't want to stay, they waste everyone's time."

"Once dropouts see that it is difficult to make it without an education, perhaps they would then work harder than anyone in school to see that they got through."

Others believe that there would be better cooperation if attendance were voluntary and recommended a "flexible school system, which could handle individual needs and enable students to be in school-work programs instead of leaving school for a job."

Confidential medical treatment

Only two out of five of the students who commented were interested in confidential medical care for teenagers, and one third of these believe that the age limit should be much lower than 21—from 15 (a few) to 18. Almost one half said there should be no age limit at all:

"A doctor's visit is supposed to be held in confidence. It is for adults and should be for us."

Another Reporter explained:

"In an unfortunately large number of cases, adolescents refrain from obtaining medical assistance because it would involve the embarrassment of informing one's parents. We feel that it is essential that teenagers be given without parental consent any medical treatment that is necessary to preserve their health and special prescriptions such as birth control pills that a doctor agreed were safe and for which there was a justified need."

A minority of five students endorsed the present age, or recommended that it be higher.

The issue of medical care probably impinges on family relationships more than other issues since problems here—as when a student seeks a prescription for contraceptives, treatment for venereal disease, or requires emergency help for a drug overdose—are almost certain to conflict with strongly held family values.

Many students expressed misgivings or more conservative values about the ease with which medical treatment should be made available. One young man recommended confidential treatment for venereal disease, but not for birth control. Another wanted parents specifically informed about VD and birth control, but not about other less controversial services.

Some students would also limit "medical freedom" to those able to meet the required payment.

Marriage and parenthood

Youth Reporters seemed to lack familiarity with the legal requirements in their respective States governing the age at which young people may marry without paren-

tal consent. (The age varies, but is below 21 for girls in many States.) Such permission is the major exception to ordinary contract laws, which specify 21 as the age of majority. This is the only area in which adult status may be granted to women earlier than to men, an exception which seems related to standards of male financial responsibility.

A little less than one-third of the Reporters responded to this item. Their opinions were relatively conservative, and two major views emerged. The largest proportion—about a third—think the present age is about right. Their comments seem to indicate wariness and an unwillingness to move into this adult arena. The other major view, expressed by a fourth of the Reporters responding, insists that there should be no age limit related to parental consent. This group seems more concerned with parent-child relationships and the autonomy of the youth generation, than with age per se: "Parents shouldn't be able to veto."

A few recommended 21 as the right age. Only one Reporter in ten believes the age restriction should be lowered. Among this group, the most frequently specified age is 18—the age suggested by the American Law Institute in its model legislation regarding age of marriage, without parental consent, for both men and women.

Closely related to the issue of appropriate age for marriage were the responses to the question of appropriate age to have a first baby. An analysis of the responses to the latter question indicates that many Reporters interpreted it as what is the appropriate "*legal* age to have a baby"? and accordingly said that there should be no age limit, or that parenthood could not be legislated.

A number of comments, however, represented a range of teenage thinking: "babies should come after marriage", "if parents won't consent to their early marriage, girls take revenge on them and get pregnant," and "with today's growing population, young people should be encouraged to limit the number of children they have."

Juvenile court cases

On the question of age status in juvenile court cases, opinions varied widely. According to present practices, youths 18 years of age in most States and 16 years of age and older in a few States (or younger with a waiver from the juvenile court) are treated as adults, and are tried in criminal courts. While almost one-third of the students commented on the issue, only a few ranked it as either important or unimportant. Of the one-third stating an opinion, slightly over one-fourth rated the present age as satisfactory, while an equal proportion feel that if the age were lower, it would serve to deter crime and college militancy. About the same number believe that the age should be higher.

"The law is trying to protect people from themselves."

"It is unfair for a person as young as 14 to be tried as an adult in a criminal case when this person is given absolutely none of the privileges of an adult."

Some students feel that there should be no specific age limit and that the present juvenile court system is unconstitutional. These students tended to recommend that all young people should be treated as adults, and that decisions should be individualized.

Cigarettes and liquor

The restrictions on access to cigarettes and liquor are considered irrelevant because the law isn't enforced. However, almost half of the Reporters feel that the legal age for access should be lower, and 8 percent want no restrictions at all. Some students see smoking and drinking as behaviors adopted to look "cool" or to rebel against authority.

One fourth of the Reporters believe that the present age in their State is fair and a few feel strongly that adequate enforcement of restrictions would discourage younger students from smoking and drinking.

Judging from the fact that they seem to ignore the health factors involved in smoking and drinking, it would seem that more effective education is needed in this area.

Financial responsibility

While the Reporters generally favor lower ages for assuming financial responsibilities, they apparently have little information about the responsibilities involved in such practices as installment buying, rental leases, and other aspects of adult life. The responses also indicate that these young people are not aware of their lack of information, strongly suggesting that more educational programs are needed in this area, too.

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an essay review

MENTAL RETARDATION AS A SOCIAL PROBLEM

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Margaret Adams has written an excellent book on the social dimensions of mental retardation.* With clarity and sensitivity she has presented the "malevolent stereotype" of mental retardation and described its effects on society's treatment of the mentally retarded.

However, Miss Adams, a consultant in social work at the Walter E. Fernald State School in Massachusetts, has not limited the scope of this book to practitioners in the field of mental retardation and social work. Miss Adams writes from broad experience as a caseworker both in the United States and England. The book has broad application to the problems that relate to chronic disability—be they physical, social, emotional, or intellectual—faced by professionals in all disciplines.

We know that people follow similar patterns in responding to stress and crisis. But their specific problems vary, requiring adaptation of the basic helping process to fit the particular situation. Helen Harris Perlman has said that the essence of social casework lies in its aims to facilitate the individual's social adaptation—to restore, reshape, or reinforce his functioning as a social being. It is precisely this general concept of social adaptation and social functioning that Miss Adams discusses in its specialized application to the problems of the mentally retarded.

I don't know of any other book that gives a clearer, more logical explanation of the importance of viewing mental retardation as a social problem or a better presentation of the variety of social services needed by the mentally retarded. The first two chapters on the socioclinical nature of mental retardation and the historical background to services sum up complex topics in a lucid well-organized fashion. Miss Adams sets the conceptual framework for her presentation of social dimensions at the same time that she discusses the nature and characteristics of mental retardation.

All of us in the helping professions—social workers, doctors, nurses, teachers, rehabilitation counselors—are now being asked to work together in preventive and rehabilitative programs. Federal legislation has fostered a coordinated, interdisciplinary approach to maternal and infant care, Model Cities, community health, community mental health, and other welfare and educational services. This book spells out the applicability of an interdisciplinary approach in one problem area and could therefore serve as a model in other areas.

Mental retardation is, of course, not the only area in which society has been unwilling to assume full responsibility for prevention and rehabilitation. Another example is the chronically dependent population that requires public assistance. Miss Adams cites many parallels between the areas: the lack of sufficient funds for prevention, rehabilitation, and basic maintenance; the social isolation; the punitive legislation; and the denigration of professionals who work with the people affected.

I think that services to the mentally retarded can serve as a barometer of a nation's willingness to support its dependent citizens.

Time-currency society

How willing are we to assume responsibility for helping the chronically dependent? Perhaps we should take a lesson from Edward de Bono in finding new solutions to our old problems.[1]

" 'Conventional thinking' is 'vertical,' which means that you accept fixed concepts and move forward from them toward a solution," he tells us. " 'Lateral thinking,' on the other hand, allows you to escape from fixed concepts and move sideways in an attempt to look at things in a different way. Vertical thinking takes place after you have accepted fixed concepts; lateral thinking takes place before you have found new ones."

Professor de Bono, who teaches mathematics and investigative medicine at Cambridge University, has suggested that we adopt a time-currency concept in which effectiveness rather than efficiency becomes the basis for society's evaluation of an individual's contribution. This would replace the current value-currency concept "in which the value provided by a person's work is exchanged for the value he absorbs as cost."

*MENTAL RETARDATION AND ITS SOCIAL DIMENSIONS. Margaret Adams. Columbia University Press, New York, N.Y. 1971. 396 pp. $10.

Efficiency, as defined by de Bono, means obtaining as high an exchange rate as possible. If one man paints a lamppost in 2 hours, that is efficiency. If 10 men paint the same lamppost, that is not efficiency—but it still is effectiveness.

"In a time-currency society a person is under no obligation to provide value," de Bono explains. "Instead, he provides time. Thus students, the unemployed, and people who have time and energy left over after competing in the value-currency society can become part of the urban solution by caring for the environment or for other people. In return, they can receive pay and services." I believe this approach, if properly applied, could revolutionize our view of the value of the mentally retarded as members of society.

The problems of the mentally retarded cannot be separated from those of society as a whole, Margaret Adams asserts. In her analysis of the social dimensions of mental retardation, she has rightly transferred emphasis from the traditional medical and clinical aspects to broader human aspects. Viewed as a medical problem, mental retardation appropriately employs the clinical model of diagnosis and treatment. Viewed as a social problem, however, mental retardation requires the public health model of prevention and intervention.

Miss Adams points out a most significant statistic: of the total population of mentally retarded in the United States, 11 percent fall within the ranges of severe retardation and 89 percent fall within the ranges of mild retardation. Because economic and social deprivation is a major cause of retardation, the majority of the mildly retarded come from poor families.

After World War II pressure groups for the mentally retarded were organized by middle-class parents, Miss Adams recalls. Spurred on by their concern for severely retarded and organically-physically handicapped children, the pressure groups have focused their efforts on obtaining expanded facilities, funds for basic research, and programs for the severely retarded. For example, most States have enacted legislation to detect phenylketonuria in the newborn, although the disease affects a very small percentage of the total population of mentally retarded.

Only recently has there begun to be a recognition of the parallel need for legislation to help the large number of the mildly retarded who live with their families instead of in residential institutions. The changing emphasis takes notice of the mentally retarded both as deprived members of society entitled to a first claim on social services, and as persons who can benefit from and respond to a social approach to their problems. As a result more money and services are beginning to be provided to the mildly retarded.

Social work factors

Two key factors emerge for social work consideration, the author says. One is that basic social work principles are applicable to the mentally retarded. The same methods of case work, group work, and community organization that produce a positive response from any client also can produce constructive interaction with the mentally retarded and their families. Miss Adams recognizes that social workers need some specialized knowledge to work with the mentally retarded, but she says it can be made available through consultation or inservice training.

The second key factor is the involvement of the client in his own helping process. Both public and voluntary social agencies have made significant progress in maximum feasible participation of clients in policymaking, staff hiring and firing, and budget allocations. In addition the agencies are making their clients responsible for using the help that is offered.

For the mentally retarded, who are limited in their intellectual ability, maximum participation in all realistic decisions leading toward independence is especially important. This is a chain reaction: people treated with the expectation of good behavior tend to behave more independently, thereby creating more acceptance for themselves.

Although this is by no means a "how to" book, there is practical discussion of the techniques and skills needed to help the mentally retarded and their families, with a wealth of case excerpts that illustrate precisely the points enumerated. Miss Adams gives an excellent explanation of the social work technique of encouraging the client to discuss a problem through narrative presentation.

In a group or interview, the social worker who uses this technique asks the client what she *did* about her feelings at a time of crisis. For example, the social worker might pose the question, "When you first found out that your child was mentally retarded, what did you do?" In this process the client makes constructive responses about her behavior instead of recounting negative feelings.

In chapter after chapter, Miss Adams shows the importance of continuously making options and choices available to the mentally retarded client, and reasserts that concrete services are as necessary as sensitive counseling. She points up the need for a continuum of services to meet the ebb and flow of the client's demands at different points of crisis in a life cycle. In a masterly summary Miss Adams outlines the essential components of a community organization program.

The chapters "Some Concepts of Casework" and "The Professional Relationship With the Mentally Retarded Client" offer much for practitioners to apply to their own practice.

"Mental Retardation and Its Social Dimensions" should, I believe, stimulate the thinking of all persons concerned with the social dimensions of chronic problems, regardless of their disciplinary affiliation. It is an important addition to the literature as well as a pleasurable one because its style makes this book a joy to read.

[1] New think for New York . . . Cf/Edward de Bono. *New York Magazine*. April 5, 1971.

HERE and THERE

H.R. 1—developing standards

Under the New Social Services Provisions of H.R. 1, now before the Congress, $150 million would be authorized for payments for foster care and adoption services. This would mark the first time that a substantial amount of Federal funds would be made available for these services.

The proposed legislation also provides that payments for foster care be made only to an agency, institution, or person whose care meets standards prescribed by the Secretary of the Department of Health, Education, and Welfare.

Several task forces and committees have been working since midsummer to establish standards for foster family home care and institutional care.

Taking the lead in this activity is the Office of Child Development, the standard setting agency for children's services in the Department. It is working in close collaboration with the Community Services Administration, Social and Rehabilitation Service, which would administer the funds and implement the standards.

A national committee composed of representatives of the Child Welfare League of America, the American Public Welfare Association, OCD, CSA, and other Federal and State agencies met late in July to discuss the project. Task forces were then formed to develop standards in specific areas.

Beatrice L. Garrett of the Children's Bureau, OCD, heads the National Task Force on Federal Standards on Foster Family Services, a 14-man group whose members are preparing draft standards to cover the 35 areas identified within the broad field of foster family services. They include representatives from each of the 10 regions served by the HEW field offices—foster parents, directors and staff members of State agencies and representatives of urban and voluntary agencies.

Each member of the national task force, in turn, has formed a committee to consider standards related to two or three of the major areas to be covered. The final draft standards will also include criteria for judging how well the standards are being met in the States.

Draft standards for institutional care of children are being drawn under the leadership of Martin Gula of the Children's Bureau, OCD. The standards are being discussed and reviewed in a series of regional meetings attended by representatives of Federal, State, and local agencies, administrators of residential institutions and those most directly affected by the standards—the children who are being cared for in the institutions and their parents.

H.R. 1—day care planning

The Office of Child Development has established a Federal Interagency Policy Group on Day Care Planning to guide overall planning for day care aspects of H.R. 1, now pending before the 92nd Congress. The proposed legislation calls for the development and purchase of day care services, with programs to be implemented upon enactment.

Under the chairmanship of Saul Rosoff, deputy director of OCD, the 20-member group is composed of representatives of the Department of Labor, the Office of Economic Opportunity, OCD, Social and Rehabilitation Service, Welfare Reform Planning Office, Office of Education, and the Office of the Secretary in HEW. The policy group has been meeting biweekly since July to consider policies and options regarding day care and to recommend a coordinated strategy for carrying out the Federal responsibilities—including standards for child care and the development of facilities.

Staff members from agencies having a special interest in day care planning have been assigned to an OCD team working under the policy group's general guidance.

Policy papers, proposed regulations, guidelines, and administrative procedures are being prepared, together with estimates of day care resources and needs. Priorities for Federal funding are also being considered.

Day care needed

As of December 31, 1970, about 3,600 mothers eligible for the Work Incentive Program (WIN) could not be referred for enrollment by welfare departments because of lack of child care arrangements. Reports from 45 States show that arrangements for care were not available for 8,500 children receiving aid to families with dependent children (AFDC); of these, a little less than half were under 6 years of age and the rest were between the ages of 6 and 14. Their mothers comprised a little less than a tenth of those who needed child care arrangements in order to accept work or training in the reporting States.

In the 3-month period ending December 31, 1970, the number of mothers and other caretakers enrolled in the WIN program increased by 5 percent and the number who could not be enrolled solely because of lack of child care arrangements decreased by 3 percent from the previous quarter.

Of the 127,000 children whose mothers were enrolled in the WIN program in 48 reporting States on December 31, 1970, almost half were cared for in their own homes, a tenth in relatives' homes, a fifth in day care facilities (over half of which were family day care), and a fifth under other arrangements. The latter group included 4,000 children aged 6 through 14 who looked after themselves.

Dental education

A 2-year dental education demonstration project that enables sixth grade students to discover for themselves the cause and prevention of some dental diseases was initiated in some Cleveland schools this fall by the city's Department of Public Health and Welfare. The project will include 3,000 children—

1,500 in the study group and 1,500 in a control group.

The project is an expansion of a 1970–71 pilot study, which was conducted with 200 sixth grade students from middle- and low-income families, including Polish, black, and other ethnic groups. It is based on two assumptions: (1) a change is needed to make the traditional methods of teaching dental care more relevant for children and teachers, and (2) children will be motivated to follow proper dental practices if they are aware that tooth decay and periodontal disease may be caused by plaque, a bacterial infection that can be controlled.

About 100 persons—dentists, dental hygienists, dental students, and classroom teachers—have been trained in the special technique for teaching dental health. The success of each group in motivating children to control or prevent dental caries and periodontal disease will be measured through dental examinations of all children in the project every 6 months.

In the project, dental health is presented to participating sixth grade students as a special unit of health education, with 1-hour classes each day for 5 consecutive days. First the teacher describes plaque as an extremely sticky, clear or whitish film that attaches itself to the teeth and produces acid.

Students learn to take samples from their teeth and examine the living bacteria under a phase microscope; they also learn to use a disclosing solution to identify plaque that may be overlooked on a visual examination. The lessons also include chemical demonstrations of acid production in the mouth, the role of nutrition, three short movies on dental health, and instructions on staining, flossing, and brushing teeth to prevent or control the buildup of plaque. During the next 2 school years, students will examine each other's teeth weekly for plaque.

The sixth graders are encouraged to teach members of their families why and how dental diseases occur and what can be done to stop such diseases. Written instructions and diagrams of methods for controlling plaque will be distributed to families, supplemented by a dental health information program using radio, television, and newspapers.

Charles A. Clark, D.D.S., dental planner in the Division of Community Oral Health, is director of the project. (Address: Department of Public Health and Welfare, Room 23, City Hall, 601 Lakeside Ave., Cleveland, Ohio 44114.)

Mental health

The National Institute of Mental Health is marking the 25th anniversary of the passage of the National Mental Health Act by the publication of "The Mental Health of the Child," a compilation of 42 selected reports on projects it has supported in the field. The book is designed, as Institute Director Bertram Brown notes in the foreword, to serve as ". . . a reminder of the beginnings that have been made—and of what more we can do. It is intended to stimulate further the creative approaches of research personnel and to provide information of value to clinicians and all those others who deal directly with the child . . ."

Grouped into four major areas the reports cover studies and demonstrations in prevention, factors that influence a child's mental health, advances in diagnosis and treatment, and basic studies of child development. Although most of the reports have been published before—in the Institute's "Research Project Summaries" and "Program Reports" series—seven, which describe recent advances, are new.

These include three appearing in the first section, which looks at the child in his normal environment at home, in school, and in the community. They cover "Nursery Schools in the Service of Mental Health," which reports on a project planned to promote interfamily, interrace relations; "A Pre-school Program for Disadvantaged Children," which describes a program serving 3-year-olds from low-income, Spanish-speaking families; and "Operation Hope: Educating New Leaders," an experimental training program in which 20 students from Los Angeles ghettoes are being helped through college and encouraged to prepare for careers in mental health professions.

Other new studies reported are "Schizophrenia: New Light from the Life Histories and Biochemistry of Siblings and Twins;" "Studies of Child Abuse and Infant Accidents," based on research conducted by the staff of Children's Hospital in Pittsburgh; "Infant Stimulation as Part of Well Baby Care," a research program conducted with unmarried teenage mothers at Washington, D.C.'s Children's Hospital; and "The Development of Intelligence in Babies," a study conducted by Jerome S. Bruner, director of Harvard University's Center for Cognitive Studies.

("The Mental Health of the Child: Program Reports of the National Institute of Mental Health," Public Health Service Publication No. 2168, 1971, 588 pp., $5. Copies are available from the Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402.)

Mental retardation

In Rochester, N.Y., plans for a new State institution scheduled for opening in 1973 have already resulted in steps to strengthen and expand community resources for children with developmental disorders and to tie the institution's program closely to other community programs. To be known as the Monroe Developmental Center, the institution will provide residential care, training, and other services to children and young people who suffer from mental retardation, emotional disturbance, or brain injury.

A pediatrician, Albert P. Scheiner, is center director. Since 1969 he has led a task force and the center staff in developing a coordinated program of comprehensive care for the mentally retarded in Monroe County.

The task force is comprised of representatives from the city school system, the University of Rochester School of Medicine and Dentistry, minority groups, mental health agencies, and consumers. The coordinated program includes—

- Outpatient services, provided by the Community Diagnostic Clinic operated by the Monroe County Association for Retarded Children. The clinic was opened in January 1970. Its services include a home care program staffed by a social worker and home aides for children too young or too impaired to participate in a center-based program; a diagnostic and habilitation program; a screening program conducted by an occupational therapist and a speech pathologist; an innercity preschool habilitation program conducted in the child's home community; and a diagnostic classroom.
- Residential care, to be provided by the Monroe Development Center. The center will emphasize short-term habilitation but will also accept children for

permanent care. The center's staff is already coordinating services of 18 community agencies.

- Teaching and research in developmental problems, provided by the University of Rochester medical school for physicians, psychologists, medical social workers, and other professional persons. The university's teaching-oriented Diagnostic Clinic for Developmental Disorders shares its staff with the Community Diagnostic Clinic. When the Monroe Developmental Center opens, it will be used as an observation and training resource by the university.
- Evaluation of the community's health services to the retarded. The university and the center will conduct evaluation on a continuing basis.

The basic planning for the center has been supported through local, State, and Federal funds, including a grant from the Rehabilitation Services Administration. (For further information: Monroe Development Center, 797 Elmwood Avenue, Rochester, N.Y. 14620.)

Advocacy

A new newsletter, *Advocacy for Children*, has been initiated by the National Center for Child Advocacy, with the guidance of an HEW interagency editorial advisory board. Designed for persons actively engaged in advocacy programs at State and local levels, *Advocacy for Children* will be issued periodically.

Since there are many interpretations of advocacy and many activities included under the term, the newsletter will contribute to clarification by reporting on activities throughout the country that are so identified.

For further information, write Jean Reynolds, National Center for Child Advocacy, Children's Bureau, Office of Child Development, Box 1182, Washington, D.C. 20013.

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Six demonstration projects involving child advocacy are getting started this fall under grants totalling $656,000 awarded jointly by the Bureau of Education for the Handicapped, Office of Education, and the National Institute of Mental Health, Health Services and Mental Health Administration. The two HEW agencies are working together through a Joint Planning Committee for Children, which selected the six projects from 33 applications.

All child advocacy projects seek to increase public awareness of the social, educational, and emotional needs of children and to improve community resources that serve children. Recipients of the 1-year grants are Central City Community Mental Health Center, Los Angeles; Prince Georges County, Md., public schools; Learning Institute of North Carolina, Durham; Philadelphia Urban League; Dede Wallace Center, Nashville, Tenn.; and Mexican-American Neighborhood Civic Organization, San Antonio, Tex.

Family day care

The School of Education at the University of Michigan is conducting a training and research program in the field of family day care, with a 1-year grant under Title IV–A of the Social Security Act.

Training is being provided for 24 low-income and lower-middle-income women who are licensed day-care mothers. Biweekly home visits are made by consultants who have received training and experience as teacher assistants in other early childhood programs. The consultants also receive continued training in the theoretical areas and techniques necessary for training day-care mothers.

Depending on the needs and interests of the day-care mothers, the consultants assist the mothers in organizing the day or arranging the physical setting, or both. Montessori methods, games, indoor and outdoor activities are taught to those day-care mothers that are interested.

In addition, the day-care mothers attend biweekly group meetings led by a student social worker with the assistance of the project director, a specialist in early childhood education, where they attempt to solve common problems through discussion. Several group meetings are set aside for workshops in art, music, and creative dramatics.

The goal of the project is to provide the day-care mothers with sufficient training and knowledge in child care and development to give them a sense of professional competence, and also to provide the consultants who are trainees themselves with a step upward. The consultants are employed on a half-time basis and receive stipends to enable them to finish academic work for a bachelor's degree in education.

The research component of the project will provide a picture of the family day-care mother—her attitudes, concerns, and her environment—and will attempt to measure the effects of the training program on the children in care.

The project is directed by Melinda Green; the research director is Thelma Valenstein.

Adoption procedures

In response to many recent inquiries relating to adoptions, the Children's Bureau has prepared a summary of its official position on the "Termination of Parental Rights and Responsibilities and the Adoption of Children."

The Bureau has long held that the termination of parental rights and the adoption of children should require two separate judicial procedures, and that the termination procedure should be completed before the adoption petition is initiated. The parent-child relationship is so important that only through judicial action can the parent and child be completely divested of their rights and obligations to each other. And only through a judicial decree can the child legally be freed for adoption.

The Children's Bureau believes that all State laws should require these two separate procedures and that a child should not be placed in a prospective adoptive home until the parents' rights have been terminated.

Once the termination decree has been finalized, the only issue to be considered at the time the adoption petition is heard will be whether the child and the adoptive family are suited for each other. No issue regarding the natural parents' rights will then be placed before the court.

At present, only 16 States have provision for judicial termination of parental rights. The remainder have surrender, relinquishment, or release provisions, which are contractual arrangements with a social agency. The Children's Bureau considers these arrangements unsatisfactory because the rights and obligations of parents and children remain unclear.

Included in the discussion of legal steps and social services involved in adoption procedures is the Bureau's recommendation that guardianship of a child be given (at the time of the termination decree and before the child is adopted) to an authorized child adoption agency.

The 3-page summary is available from the Division of Public Education, Chil-

dren's Bureau, Office of Child Development, Box 1182, Washington, D.C. 20013.

Further information on the subject is contained in "Legislative Guides for the Termination of Parental Rights and Responsibilities and the Adoption of Children," Children's Bureau Publication No. 394, 1961 (reprinted 1968).

Children's conference followup

Plans are taking shape for the implementation of the recommendations of the 1970 White House Conference on Children, under the leadership of the WHCC Follow-Up Office located in the National Center for Child Advocacy, Children's Bureau, Office of Child Development.

An all-day August meeting in Arlington, Va., brought together representatives of 45 national voluntary and professional organizations and staff members of the Children's Bureau. A cross section of the 1970 conference participants, the representatives discussed the views and actions of their organizations in regard to fulfilling the conference recommendations and offered suggestions on what OCD could do in the field.

Later the Follow-Up Office sponsored a series of meetings that examined recommendations related to each of the 1970 conference "cluster" areas—learning, individuality, health, parents and families, communities and environment, and laws, rights, and responsibilities. Attending were leaders and participants in the 1970 White House Conference and other persons knowledgeable in the specialized areas.

Robert C. Pekarek is director of the WHCC Follow-Up Office.

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"Overriding Concerns," a 16-mm. black-and-white film that discusses the major issues of the 1970 White House Conference on Children, is being distributed nationally. It presents a conversation among spokesmen for groups of related forums, who identify the overriding concerns of the delegates. The film is available from the National Audio-Visual Center, Government Services Administration, Washington, D.C. 20409. (Rental: $15.)

Correction

CHILDREN gratuitously awarded a Ph.D. degree to Earladeen D. Badger, author of "A Mothers' Training Program—the road to a purposeful existence." (September–October 1971, p. 168.) Mrs. Badger and the editor want to set the record straight: she is a registered occupational therapist who earned a master's degree in special education from the University of Illinois in 1969.

RESEARCH GRANTS AVAILABLE

The Office of Child Development will consider applications for funding of research and demonstration projects in the following nine areas identified as priorities for fiscal year 1972 research appropriations:

Day Care

Development of models of day care which emphasize child development.

Child Advocacy

Projects conducted at the local level which demonstrate alternative methods for improving the health, education, and welfare of children.

Research on Racism

The study and development of early childhood intervention programs that deal directly with problems of racism; programs that develop and utilize the talents, skills, and experience of ethnic investigators; and projects that develop programs in coordination with black colleges and other research groups who will be helped to engage in OCD research and evaluation programs.

Parent Education

Child development and child care study programs for teenagers; projects that offer special comprehensive programs for pregnant school-age girls; and demonstration parent education programs for mothers in a variety of settings including the home and public pediatric clinics.

Programs for Children from Fatherless Homes

Demonstration projects to provide a male model for children, and projects which compare the effectiveness of volunteers, older adolescents, college students, young adults and retirees in providing such a model.

Television

Research on the impact of television on preschool children and their families and projects which compare the effectiveness of various technological developments, curriculum variations, and scheduling.

Children's Institutions

Demonstration of methods designed to effect change in the institutional care of children.

Adoption

Demonstration projects planned to increase the availability of homes for children who are difficult to place because of their age, ethnic identity or physical or mental handicap.

Emergency Services

Projects which demonstrate workable alternatives for the child who faces a traumatic home situation and/or is in the process of being removed from his home.

Further information on grants in these areas may be obtained from Duane Ragan, Office of Child Development, Research and Evaluation Division, P.O. Box 1182, Washington, D.C. 20013; Telephone: (202) 755-7740.

READERS' EXCHANGE

MITCHELL: therapy or education?

In "Occupational Therapy and Special Education," Marlys Marie Mitchell attempts to differentiate between the roles of these disciplines in the assessment, programing, and evaluation of treatments for handicapped children. (CHILDREN, September-October 1971.)

The author suggests that each professional must be well-grounded in his own discipline before a truly profitable interface can occur. Our experience in an interdisciplinary clinical program certainly confirms this concept.

One point made by the author needs clarification. Dr. Mitchell notes that the basic aim of special education is to "overcome the deficiency that has made him (the handicapped child or adult) different." However, when the deficiency is chronic, as in the case of the severely mentally retarded child, the objective in either therapy or education may be accommodation to the presses of the environment rather than remediation.

The procedures used in achieving the interdisciplinary mix deserve further elaboration. Both disciplines—occupational therapy and special education—must independently identify objectives and strategies for assessment before role negotiation can begin. Dr. Mitchell offers excellent examples of how both disciplines seek a similar objective: assessment of perceptual-motor skills, often through the same medium, such as toys.

The specific objective and the results of assessment may, however, be different for each discipline. In conjunction with the process of assessment, a set of crucial questions must be addressed by each discipline: What is the nature of the treatment program—therapeutic or educational? Who will implement the program? What are the expected outcomes? What time frame is projected? How and by whom will the program be evaluated?

After each person has assessed the case, implemented his treatments, and evaluated the effects of his prescriptions for change, the process of role assimilation can begin. The objective, then, of an interdisciplinary activity is to cause a reexamination of role expectation within and between disciplines to determine the degree of role reciprocity needed for more effective services.

Who must provide the leadership to facilitate more successful joint endeavors between the disciplines? Dr. Mitchell suggests that administrators and supervisors of programs must provide the direction. I believe it is equally important that teachers and trainers of therapists and educators at the preservice and inservice level have a major role in the demonstration of more efficient and effective multidisciplinary and interdisciplinary models of service delivery to handicapped children and adults.

Leonard C. Burrello
Program Director for Special Education
Institute for the Study of Mental Retardation and Related Disabilities
University of Michigan, Ann Arbor

BADGER: involving parents

Earladeen D. Badger hit the nail on the head when she wrote the article, "A Mothers' Training Program — The Road to a Purposeful Existence"! (CHILDREN, September - October 1971.)

I agree wholeheartedly with her statement, "Any program for the disadvantaged that directs itself to the education of *parents* hits the real target." I believe that for parent education to be truly beneficial to the child, both father and mother must be involved.

Since January 1967, I have been working first in Head Start and now in Parent and Child Center (PCC) programs that have emphasized parent involvement and parent education. In the West Virginia PCC program, parents and their very young children in isolated rural areas of Wayne and Lincoln counties are transported daily to two nearby centers, where they are provided an enriched environment and socialization experiences. The most important aspects of the centers are (1) a planned stimulation program for infants and toddlers, and (2) a planned program of parent education that emphasizes equal participation of fathers and mothers.

Parent education in the PCC centers is planned cooperatively by parents and members of the central staff (nutritionist, nurse, child development assistant, and social services coordinator). Major emphasis is given to the *total* environment of the child.

Because of lack of medical resources in these isolated communities, particular attention has been given to health and dental education, first aid, medical examinations, nutrition, use of food stamps, and principles of feeding young children. Through the program, parents have become more aware of the importance of good health care for their children and themselves.

As in the program described by Mrs. Badger, the parents have been encouraged to provide educational activities at home. At both centers, parents have learned to use toys that they made themselves to help their own children develop new concepts.

Through involvement in PCC, many formerly shy, withdrawn parents have developed self-confidence and an awareness of their personal worth. Two parents now work in Head Start, another is director of a community center, and others are enrolled in training programs.

As Mrs. Badger said, "*time* is an important ingredient in any program that hopes to effect attitude change coupled with social action." The positive results of the PCC program in West Virginia have taken 2½ years of total commitment from the staff, a belief that low-income parents *are* interested in their children and *do* want to provide a good life for them, plus mutual trust, respect, and honesty.

To quote one of the PCC fathers, "We *can* do what we *want* to do."

Mary Jane Bevins
Director, Parent and Child Center Program
Southwestern Community Action Council, Inc.
Huntington, W. Va.

EPSTEIN: education for parenthood

A procedure that could avoid or at least minimize the negative aspects of a child's failure to achieve in school was suggested by a part of the summary report on the 1970 White House Conference on Children ("Priority for Change—Some Preliminary Proposals from the White House Conference on

Children" by Noel Epstein, CHILDREN, January–February 1971.)

The topic was the need for more education in "parenting" at all levels of human development. One suggestion was for older elementary age children to receive practical experience in parenting roles by adopting a kindergarten class.

It follows that a class of older children might adopt younger emotionally disturbed children and others who had not been able to advance in school with their own age group. The older students would assume a tutoring or parenting role toward the student who is 2 or 3 years younger chronologically and educationally. Their collective role would be to teach the younger child—through acceptance and example—how to function in positive ways in a "normal" educational setting.

The provision of 20 or so older children as models of acceptable behavior for an emotionally disturbed child should encourage consistent and positive responses. The accepting and acceptable group of older children should also provide the therapeutic support that the emotionally disturbed student needs. Other positive aspects would be the removal of the threat of failure from the younger child through the help of a tutor, a reduction of the number of unacceptable or regressive actions adopted by children to maintain their egos in a failure situation, and the possibility of the child's return to a class of his own age group without being branded a failure.

As a teacher of emotionally disturbed children, I have observed how well they can function on a one-to-one basis with volunteers when the pressures of grades and required assignments are removed. Another aspect of a good volunteer-child relationship seems to be a lowering of stress on the fragile ego of the child when he is not required to make comparisons between himself and other children who are successful in school.

In summary, I propose another choice for administrators faced with the need to remove a student from a class of his own age group for unacceptable dysfunctioning. The choice is to escalate him into a majority of older children who can serve as models of acceptable behavior with all the powers of peer pressure in their favor.

Tom Baty
Beloit of Ames
Ames, Iowa

guides and reports

DIRECTORY OF FEDERAL PROGRAMS FOR THE HANDICAPPED. The Council for Exceptional Children, 1411 South Jefferson Davis Highway, Arlington, Va. 22202. 1971. 12 pp. $1. (Discount for quantities of 10 or more.)

A compilation of Federal programs specifically designed to serve physically and mentally handicapped persons, presenting a description of each program together with information on its administration, authorizing legislation, and appropriation.

A STUDY OF BLACK ADOPTION FAMILIES: a comparison of a traditional and a quasi-adoption program. Elizabeth A. Lawder, Janet L. Hoopes, Roberta G. Andrews, Katherine D. Lower and Susan Y. Perry. Child Welfare League of America, New York, N.Y. 1971. 77 pp. $2.95.

Reports on and compares family and child functioning in two adoption programs (quasi-adoption and traditional adoption) studied by the Children's Aid Society of Pennsylvania and Bryn Mawr College, and evaluates the child's adjustment within each group.

CURRENT RESEARCH IN EARLY CHILDHOOD EDUCATION: a compilation and analysis for program planners. Annie L. Butler. American Association of Elementary-Kindergarten-Nursery Educators, NEA Center, 1201 16th Street, NW., Washington, D.C. 20036. 1970. 193 pp. $5.

Summarizes research in early childhood education between 1964 and 1970, including the current scene, intellectual growth, school achievement, and such diverse areas as early stimulation, parent involvement, the importance of learning to learn, and creativity.

CHILDREN WITH HEART DISEASE: a guide for teachers. American Heart Association, 44 East 23d Street, New York, N.Y. 10010. 1971. 15 pp. $7.40 per 100.

Suggests guidelines for teachers to use in recognizing and managing children with signs of illness that may lead to heart disease and children who already have heart problems.

SEX EDUCATION ON FILM: a guide to visual aids and programs. Laura J. Singer and Judith Buskin. Teachers College Press, Teachers College, Columbia University, New York, N.Y. 10027. 1971. 170 pp. $3.95.

Describes audiovisual materials produced in the past decade related to sex education.

STANDARDS FOR DAY CARE CENTERS FOR INFANTS AND CHILDREN UNDER 3 YEARS OF AGE. American Academy of Pediatrics. Post Office Box 1034, Evanston, Ill. 60204. 1971. 23 pp. $2.

Contains basic standards developed by the Committee on Infant and Preschool Child of the American Academy of Pediatrics for day care for young children.

TRAINING NONPROFESSIONAL COMMUNITY PROJECT LEADERS. Janice R. Neleigh, Frederick L. Newman, C. Elizabeth Madore, and William F. Sears. Behavioral Publications, 2852 Broadway—Morningside Heights, New York, N.Y. 10025. 1971. 59 pp. $3.25.

Describes a demonstration study conducted by Dona Ana Mental Health Services in Las Cruces, N. Mex., in which nonprofessional mental health workers were trained to develop and lead a community service project under the guidance of a professional consultant.

INDIVIDUAL AND GROUP SUPERVISION IN FIELD INSTRUCTION: a research report. Esther Sales and Elizabeth Navarre. School of Social Work, University of Michigan, 1065 Frieze Building, Ann Arbor, Mich. 48104. 1970. 83 pp. $2.25.

Reports on a project to test the benefits of group supervision of social work students in agencies as compared with benefits of individual supervision.

U.S. Government Publications

Publications for which prices are quoted are for sale by the Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402. Orders should be accompanied by payment. Twenty-five percent discount on quantities of 100 or more.

PRELIMINARY REPORT: First National Conference of Foster Parents. HEW, OCD. Publication No. (OCD) 72-5. 1971. 62 pp. Single copies free from OCD.

A preliminary report of the First National Conference of Foster Parents held in Chicago, Ill., May 7-9, 1971.

SAFE TOYS FOR YOUR CHILD. HEW, OCD, Children's Bureau. Children's Bureau Publication 473. 1971. 8 pp. 20 cents.

Offers some tips for parents in the use and selection of safe toys for their children.

ISSUES IN HUMAN DEVELOPMENT: an inventory of problems, unfinished business and directions for research. Victor C. Vaughn, III, M.D., editor. HEW, National Institute of Child Health and Human Development. 1971. 217 pp. $1.75.

Presents 18 papers and extracts of discussions held at a symposium covering such subjects as early influences on children's development, physical and chemical aspects of growth, socialization in early childhood, cognition and learning, adolescence, and the impact of urban environment and institutions on human development.

RESEARCH RELATING TO CHILDREN: bulletin No. 27 (June 1970-February 1971). ERIC Clearinghouse on Early Childhood Education, OE. 1971. 138 pp. $1.50.

Contains brief descriptions of current or recently completed research studies dealing with child growth and development, special groups of children, the child in the family, socioeconomic and cultural factors, educational factors and services, social services, and health services.

SICKLE CELL ANEMIA. HEW, PHS, National Institute of Arthritis and Metabolic Diseases. 1971. 8 pp. 10 cents.

Describes briefly the cause, symptoms, and treatment of sickle cell anemia and gives current information about the disease.

FOUR-C: COMMUNITY COORDINATED CHILD CARE. HEW, OCD, 1971. 8 pp. Single copies available from OCD.

Describes the concept, goals, and operation of the 4-C program.

VISION SCREENING OF CHILDREN. HEW, PHS, Health Services and Mental Health Administration, Maternal and Child Health Service. PHS publication No. 2042. 1971. 24 pp. 25 cents.

Summarizes the main principles, problems, and methods in vision screening and briefly reviews the estimated prevalence of eye problems among children.

HEW refers to Department of Health, Education, and Welfare; OCD, to Office of Child Development; PHS, to Public Health Service; SRS, to Social and Rehabilitation Service; OE, to Office of Education.

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